**Baseline Study of the Disability Support System in the MidCentral Area: Disabled People’s Report**





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# 1. What is happening in the MidCentral Area

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018.[[1]](#footnote-1)

The transformed system is based on the Enabling Good Lives (EGL) vision and principles. Mana Whaikaha aims to give disabled people and their whānau:

* more options and decision-making authority about their supports and lives
* to improve their wellbeing outcomes, and
* to create a more cost-effective disability support system.

## Evaluation context

Mana Whaikaha will require ongoing evaluation to help everyone understand if its objectives are being achieved, where improvements are needed and how the approach should be adapted or expanded.

A high-level evaluation approach was developed, with advice from the Monitoring and Evaluation Working Group, as part of the overall work programme for designing the MidCentral area prototype.

*Overview of the evaluation framework*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Longitudinal outcomes** | **Baseline study** |  | **18-month outcomes** |  | **3-year outcomes** |
| **Qualitative interviews and surveys** |  | Qualitative interviews and surveys |  | Qualitative interviews and surveys |
| **System mapping** |  | System mapping |  | System mapping |
| Quantitative analysis using IDI data[[2]](#footnote-2) |  | Quantitative analysis using IDI data |  | Quantitative analysis using IDI data |
|  |  | Impacts |  | Impacts |  |
|  | **SCBA[[3]](#footnote-3)** |  | **SCBA** |  | **SCBA** |

As shown in the diagram above, the evaluation has two key inter-related components:

* Longitudinal outcomes evaluation:
  + to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau
  + to determine how the system is changing over time and to what effect
* Social cost benefit analysis (SCBA) to value the impact of Mana Whaikaha.

In addition, a developmental evaluation will be used to support the ‘Try, Learn and Adjust’ approach being adopted for Mana Whaikaha, and to help drive meaningful change throughout the prototype period.

The Baseline Study reports include information from the qualitative interviews, surveys and system mapping parts of the evaluation (the components in the diagram above highlighted on the previous page in green).

# 2. Why we did a Baseline Study

With change about to happen, we wanted a clear picture of how things were before the change (ie, the MidCentral prototype/ Mana Whaikaha) started.

The Baseline Study describes and measures what was happening before Mana Whaikaha started on the 1st October 2018. Having this information means we can repeat the study and find out what has changed as a result of doing things differently.

# 3. What the Baseline Study looked at

The overall Baseline Study had three main objectives:

**Objective 1:** to develop a detailed ‘map’ of the current disability support system in the MidCentral area

**Objective 2:** to understand and measure the current experiences and life outcomes of disabled people and whānau in the MidCentral area

**Objective 3:** to identify what support is needed to help disabled people, whānau, service providers and community-based organisations in the MidCentral region prepare for system change.

This report focuses on responses to the following questions:

* How disabled people experience the current disability support system and what impact does it have on their lives?
* How well does the current disability support system support disabled people to live the lives they want?
* Do disabled people experience the current disability support system differently? If so, how and why?
* What life outcomes are disabled people achieving under the current disability support system?
* What is most important to disabled people in creating a life they want?

# 4. How we did the Baseline Study

The Baseline Study was made up of six types of work:

1. Talking with disabled people
2. Talking with whānau
3. Surveying service providers
4. Surveying people who worked for service providers (workforce survey)
5. Talking with people who worked for a range of government agencies and other stakeholders, eg Disabled Persons Organisations (DPOs).
6. Reviewing documents that described the disability support system.

People were picked by chance (stratified random sample). It was important that there was a range of disabled people who represented all different types of people who were connected with disability support services.

Categories of disabled people were developed based on impairment/disability type, level of assessed need and age. Approximately ten percent of people from each of the three main types of disability were randomly sampled. We also assigned proportionally similar numbers of people to each group relative to their assessed needs. These groups represented people with learning and physical disabilities and people with Autism Spectrum Disorder (ASD). A sample of children and young people were also drawn at random within each category dependent on the proportion of children/young people to adults in each group.

Involved disabled people were asked for permission for their family member to also take part in the survey.

The survey involved a number of sections that attempted to review important things relating to personal experiences of disability and of the service system. These criteria were based on other survey tools in the sector and on documents such as Enabling Good Lives (EGL)[[4]](#footnote-4). EGL has the guiding principles behind the development of the new system.

Gathering information for the Baseline Study took place between early August and late September 2018.

During the interviews disabled people worked their way through the survey with an experienced interviewer.

The survey included open ended (long answer questions) and some where people gave scores on a five-point scale (Likert Scale). People were encouraged to say whatever they wanted in addition to the survey questions. Approximately half the group gave permission to have their interview audio taped.

All participants received an information sheet and consent form.

Interviews were confidential. All the information was put together to create a picture of what life was like before change happened.

## Method of analysis

The main method of analysis of survey items was the use of frequencies (percentages) for each question. Where comparisons are made between groups a simple significance test was used to tell us if the difference between each group was actually a clear or statistically significant difference. We used the Wilcoxon Mann-Whitney (WMW) test for non-parametric statistics for this purpose.

On some occasions we grouped questions together and used averages. This was the case if we were looking for general trends in similar questions, such as satisfaction with support services. *These grouped questions are only a guide or a taster.* However, they lead into further more intensive review of what is actually being said within individual questions.

On other occasions we reported averages for questions that provided a range of responses (continuous or non-discrete responses).

## Satisfaction and wellbeing – cautions when interpreting some subjective results

Satisfaction is a difficult concept to define. Satisfaction can include thoughts such as how ‘happy’ a person is or how ‘pleased’ they are with something. It can be objective in terms of having something tangible, such as equipment. Satisfaction can also be subjective, in terms of satisfaction with staffing.

**When we talk about satisfaction in this report, we are only referring to how people view the supports that are provided through/after their needs assessments with Enable (the local needs assessment and service coordination service or NASC) and prior to Mana Whaikaha on October 1st, 2018.**

About half the disabled people answered on their own behalf. The remainder were responses from someone who knew the person very well (*not* including support staff) who we refer to as their proxy. For many satisfaction questions, proxy respondents did not or were not comfortable in providing responses and these were either left blank or ‘not applicable’ was indicated.

Measures relating to satisfaction with services are initially reported as a grouped or overall suggestion of satisfaction. However, individual questions each answer a unique construct of their own which added together may not provide a sufficiently definable construct of satisfaction, especially in a survey (as contrasted with a normative tool). For this reason, grouped responses to satisfaction are balanced against individual responses to specific questions and in relation to who is making the response.

Example

A finding that surprised some is that almost three-quarters of disabled adults, who completed the survey, were generally satisfied with the disability support services they received. However, as an overall percentage this should be treated with caution since each question in the group represents an independent construct. It also needs to be read against other Likert scale measures in the survey, such as autonomy, social isolation, community participation and subjective wellbeing, which paint a far less positive picture.

**Wellbeing is a subjective indicator that asks people about their personal life satisfaction or happiness.**

These questions are intrinsic to a person and only that person will be able to provide a valid response. Proxy respondents are not used in any analysis of subjective wellbeing.

Ideally, many variables need to be considered when reviewing the findings in this report. Such as what the question is asking and who is responding. We also consider issues such as:

* Acquiescence: people may wish to please the interviewer or others with their responses (this can be a particular challenge with people who have learning disabilities).
* Lack of alternative viewpoints: for example, people with disabilities and their supporters may view the support system as working perfectly because they do not know of any other alternative.
* Low expectations and gratitude: having some help, when there was none previously, can result in relief and gratitude, without an understanding of what may be possible.
* Hegemony: people may be genuinely positive about the support system because they are heavily invested in the system in various ways[[5]](#footnote-5).
* Homeostasis: we are aware that people can adapt to their situation in a manner that they reach an acceptable degree of subjective satisfaction either with services or their own life (wellbeing), even when others (outsiders) may judge the situation quite differently[[6]](#footnote-6).

## Non-responses or ‘not applicable’ responses

For some questions proxy respondents could not or would not answer a question as some questions are very subjective. This was reassuring, as proxy respondents were asked to answer questions as if they were the person concerned. For these questions the proxy would either not respond to the question or indicate ‘not applicable’.

There were some questions not answered by some disabled people. We designed the survey so that it did not overly tire individuals. Priority questions where highlighted so interviewers could focus on these first, particularly if they were concerned the person may find it difficult completing the whole survey. Twenty people (12 percent) used this method exclusively for the seven final sections of the survey (what is often referred to as the Likert scale questions). Four more people (2 percent) completed the survey up until the last seven sections.

Some disabled people did not answer some questions (ie, ‘not applicable’ responses) because they did not know how to answer the question, did not think it was applicable to their situation, or did not understand the question.

Because of the number of non-responses (question left blank) or ‘not applicable’ responses (ticked this option), all frequencies for each individual question were calculated without non-responses (including ‘not applicable’). This was because it was not always possible to determine the motivation for either a blank or a ‘not applicable’ response.

Non-responses, as distinct from ‘not applicable’ responses, were analysed separately for the 21 priority questions (Table 1). They indicate that the average non-response was up to 6 percent for various groups. The exception to this is for those in residential services, where the rate of non-response was higher. This is discussed in the sections concerning residential homes in later sections.

**Table 1: Average rate of non-responses for 21 priority questions**

|  |  |  |
| --- | --- | --- |
|  | Average | Standard Deviation |
| Whole sample n=172 | 5.7% | 2.9% |
| Adults only n=134 | 5.5 | 3.1 |
| Children and young people n=38 | 6.0 | 4.5 |
| Learning disability adults only n=77 | 6.1 | 3.8 |
| Physical disability adults  n=48 | 3.0 | 2.6 |
| Proxy respondents only n=83 | 4.9 | 4.4 |
| Self reports only n=89 | 6.4 | 2.1 |
| Residential learning disabled adults n=37 | 9.0 | 5.9 |

The total number of non-responses *and* ‘not applicable’ responses combined, for the 21 priority questions was 16 percent on average for the whole group (172 people), and 14 percent for people providing self-reports only (not including proxies). It is higher for adults with learning disabilities (15 percent) than adults with physical disabilities only (10 percent).

# 5. Who contributed to the survey

The survey involved disabled people who were clients of Enable New Zealand.

Enable New Zealand was the Needs Assessment and Service Coordination Agency (NASC) for the MidCentral area until the launch of Mana Whaikaha on 1 October 2018. Enable is governed by the MidCentral DHB and is overseen by the Enable New Zealand Governance Group.

According to the Ministry of Health website[[7]](#footnote-7), to be eligible to receive funding from Disability Support Services (DSS), and become a client of the NASC, people need to “have a physical, intellectual or sensory disability (or a combination of these) which:

* is likely to continue for at least 6 months
* limits their ability to function independently, to the extent that ongoing support is required.

These are mainly younger people under the age of 65 years.

The Ministry will also fund DSS for people with:

* some neurological conditions that result in permanent disabilities
* some developmental disabilities in children and young people, such as autism
* physical, intellectual or sensory disability that co-exists with a health condition and/or injury”.

This survey involved a total of 172 face-to-face interviews with disabled people.

# 6. Who participated in the survey

## Type of impairment/disability

There were three distinct groups of disabled people involved in this survey. Those with a primary diagnosis of learning disability, those with a primary diagnosis of Autism Spectrum Disorder (ASD), and those with physical disabilities without other impairments (ie, they did not include people with learning disabilities or ASD). The physically disabled group did not include people with *only* sensory disabilities[[8]](#footnote-8).

**Figure 1: Disability type**

## Type of disability by level of assessed need

The level of assessed needs is based on the ratings provided through the needs assessment by Enable NZ. They include people with very high assessed needs (VHN), high and moderate needs[[9]](#footnote-9).

**Table 2: Type of disability by level of assessed need**

|  |  |  |  |
| --- | --- | --- | --- |
|  | VHNs | High | Moderate |
| Learning Disability | 38  41.8% | 36  39.6% | 17  18.7% |
| Physical Disability | 14  29.2 | 12  25.0 | 22  45.8 |
| ASD | 6  18.2 | 8  24.2 | 19  57.6 |

## Gender

Slightly more males (56 percent)[[10]](#footnote-10) are represented in the Baseline Study than females, with greater numbers of males present in the sample of children and young people when contrasted with adults (see Figure 2).

**Figure 2: Gender differences between children and young people versus adults**

|  |  |
| --- | --- |
|  |  |

## Ethnicity

The majority of the sample identified as:

* NZ European (76 percent) and
* 17 percent as Māori.

The remaining six percent represented a range of other ethnic groups and were insufficient in number to provide further analysis[[11]](#footnote-11). There were fewer Asian representatives in this sample (1.2 percent) than the total DSS population[[12]](#footnote-12) in the MidCentral area (3 percent) and only one person identified as Pasifika (or 0.6 percent, compared with the DSS MidCentral population of 2 percent).

There were few differences related to gender between the two main ethnic groups. However, differences were noted with regard to the type of disability (Figure 3) and the number of adults to children/young people who have ASD. In the latter case, Māori supported more children and young people with ASD (83 percent) than NZ Europeans (52 percent).

**Figure 3: Proportion of Māori to NZ Europeans by disability type**

|  |  |
| --- | --- |
|  |  |

## Age

Seventy-eight percent of the disabled people surveyed were adults (18 years of age and older).

The average age for people with autism spectrum disorder (ASD) was only 25 years with a range up to 35 years. Older individuals with ASD did not previously have a separate diagnosis and were represented as learning disabled. Many people with physical disabilities acquire their disability later in life (not accident related) and are, therefore, older on average than the other two groups.

**Table 3: Age by disability type**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Mean | SD | Range | CI | Total |
| Learning Disability | 43.0 | 14.5 | 18-81 | 3.3 | 77 |
| Physical Disability | 58.8 | 10.3 | 21-74 | 3.0 | 48 |
| ASD | 25.4 | 6.4 | 18-35 | 5.0 | 9 |

## Proxy respondents

**Definition:** a proxy is someone who represents someone else’s interests and views.

Approximately half of those completing the disabled persons survey (48 percent) were proxy respondents. These people were external to support services and knew the disabled person very well (usually whānau). Of this group 46 percent represented children and young people. Of the children and young people, all but one lived with whānau (one lived in a residential school).

Of those proxy respondents representing adults, 80 percent were people with learning disabilities and twelve percent were people with ASD. The majority of adults represented by proxies had very high assessed needs (VHN). Eighty-three percent of all adults represented by proxy respondents, who have VHNs, live in fully supported residential accommodation (including group homes[[13]](#footnote-13) and rest homes).

## Type of supports

### Community residential homes and people with Very High Needs (VHNs)

The majority of people living in fully staffed accommodation were adults with learning disabilities (86 percent)[[14]](#footnote-14) who live in community residential homes. These homes are run by a variety of service providers and tend to house up to six people. The average number of flatmates (not including the person) for learning disabled people, who live in community residential homes, is three (SD 1.6). There is a range of no flatmates to five people. Sixty-five percent live in homes of four or more people in total[[15]](#footnote-15) and only three of 44 people lived alone (8 percent).

|  |
| --- |
| **Approximately 90 percent of all adults with learning disabilities, who have very high needs (VHNs), live in community residential homes.** |

VHNs can include people with complex or global disabilities and related health needs, including significant cognitive impairments, physical impairments and/or sight and hearing impairments. The VHN group may also include people with less complex disabilities but significant behavioural, anxiety or psychiatric issues that require intensive support.

All twelve individuals of the people surveyed, who used to live at Kimberley Centre before it closed in 2006[[16]](#footnote-16), are represented in the VHNs group living in community residential homes (35 percent[[17]](#footnote-17) of adults with learning disabilities with VHNs living in residential homes).

Proxy respondents (welfare guardians and/or whānau) were used for many of the people with learning disabilities who were living in community residential homes (71 percent)[[18]](#footnote-18).

### Supported living and high/moderate support needs

Supported living is provided to individuals who are able to live reasonably independently in their home. While supported living does involve a degree of personal and household support, the emphasis is towards increasing the person’s independence in these activities and providing active supervision where needed. It may also involve assistance with appointments, filling out forms, budgets, diets, exercise and attending activities in the community. For most people, a person-centred, aspiration-based plan is developed and support workers assist people to pursue particular goals or aspirations.

Among those surveyed, supported living was used most often by people with learning disabilities (88 percent) who had moderate to high support needs (96 percent).

### Household management and personal care (HM&PC)

Twenty percent of the adult disabled people surveyed received only household management and/or personal care support (HM&PC)[[19]](#footnote-19). Household management involves a support worker assisting with household routines and chores according to a pre-planned schedule of activities for each person. Personal care support also provides a pre-planned schedule that is individualised for the person. Typically, support workers are provided by agencies. On occasion a person may have individualised funding and hire their own staff. Thirty-five people only received this type of support – of whom 31 were adults with physical disabilities only (89 percent).

### Whānau support and support for children/young people

There are several types of support offered to whānau or carers and children and young people. These may include HM&PC support options noted above. One of the most common is the carer support subsidy. The carer support subsidy is made available to the disabled person and their main carer, usually whānau, partner or spouse. This is to provide a time when the disabled person can be supported by someone else. Prior to the system’s change in October 2018, carer support was allocated at a daily rate of $76 a day. For a 24-hour period this equates to $3.17 per hour. On average, 34 carer support days were allocated per person. Thirty-three people in the disabled persons’ survey received the carer support subsidy. Just under half of this group *only* received the carer support subsidy (49 percent). When combined with the whānau survey, a total of 51 people received the carer support subsidy.

Another support involves out-of-home respite. This respite is provided for children and young people, usually in designated services designed for this purpose. For example, a house for around six young people. Whānau with this funding would be able to book the disabled child/young person into this service for a set number of days per year. Respite is also offered to adults. Typically, this is people with physical impairments and is often associated with designated nursing homes. Only one person, in the disabled persons survey, indicated they received respite funding (in this case individualised funding for respite where they can choose their own type of respite).

Whānau may also be offered access to the DHB Child Development Service (CDS). This is a personalised therapy-based service that provides assessment and therapy services to babies, children and adolescents (birth – 16 years) who have developmental or ongoing disability needs. They also work with babies at risk of disability, such as babies born prematurely. The service focuses on early intervention. Eight children/young people in our survey were making use of this service at the time of the survey.

Behaviour support is also offered through a behaviour support agency.

### Individualised funding, hospital and nursing home care, equipment and day services

Three other types of funding are represented in this survey. Ten people received individualised funding (IF). This was primarily in household management (seven people) and/or personal care support (seven people). One person received IF funding for respite. IF funding allows individuals or whānau to choose the style of support they desire, within particular parameters, and allows them to either hire their own staff or acquire staff through an agency.

Hospital or nursing home care was provided for two people in this survey on a full-time basis. These people may be referred to in this report with reference to residential supports but for the most part residential services refer to people in fully staffed residential homes unless otherwise stated.

Enable NZ also provides funding for equipment for most people with physical impairments who have reduced mobility or similar needs. A small number of people in this survey (seven) also received Ministry of Health funded day services.

# 7. Defining some key words and terms used in this report[[20]](#footnote-20)

|  |  |  |
| --- | --- | --- |
| **Term or word** |  | In this report, the word means: |
| **Whānau** |  | family, whānau, spouse/partner, welfare-guardian and advocates |
| **Disabled people** |  | people with a physical, learning or sensory disability, or ASD, who were clients of the MidCentral Needs Assessment and Service Coordination Service (NASC). |
| **Residential Services** |  | A community residential home funded by Disability Support Services, Ministry of Health (unless specifically stated otherwise). ‘Residential supports’ in this report refer to people who are also supported in nursing homes. |
| **Disability Support Services (DSS)** |  | Ministry of Health funded Disability Support Services |
| **MidCentral Area** |  | The MidCentral area includes Palmerston North, Horowhenua, Manawatu, Ōtaki and Tararua. |
| **Very High Needs (VHN)** |  | Very High Needs refers to a level of support, where people are identified as having multiple and significant challenges with daily living activities. The support required is likely to be intensive. The level is identified through the NASC process and based on a facilitated needs assessment. The level was developed as a consistent way to describe a person's total disability support level for their service package allocation. |

# 8. Interesting things we discovered

## Summary

There were significant variations in how people were experiencing their lives and between different groups of disabled people.

Some of the highlights and areas requiring major development are listed below:

## Highlights

|  |  |
| --- | --- |
|  | (all disabled people unless otherwise stated) |
|  |  |
| **92%** | Believe paid workers understand how to support them safely |
|  |  |
| **90%** | Believe their culture is respected |
|  |  |
| **84%** | Believe people value what they can do |
|  |  |
| **82%** | Love life (self-reports only) |
|  |  |
| **76%** | Have the equipment they need |
|  |  |
| **84%** | Believe they are supported to maintain and improve their health. |

## Areas requiring development

|  |  |
| --- | --- |
|  | (all disabled people unless otherwise stated) |
|  |  |
| **83%** | Had not worked in the week prior to the survey (adults only) |
|  |  |
| **77%** | Were single at the time of the survey (adults only) |
|  |  |
| **57%** | Chose who they lived with (adults only) |
|  |  |
| **56%** | Were achieving the things they wanted |
|  |  |
| **48%** | Had real choice about the support they received. |

The Disability Support System (DSS) in the MidCentral area prior to the Mana Whaikaha was generally meeting a variety of needs.

Many people were pleased with aspects of their support and some received all the support they felt they needed.

However, services did not appear to be assisting some people to overcome the barriers they face to live a happy and fulfilled life.

The system often provided for basic needs but did not seem responsive to the New Zealand Disability Strategy or Enabling Good Lives (EGL) principles[[21]](#footnote-21).

A major issue, identified in this report, was the structured use of funding that effectively siloed support into different packages that were tied up with inflexible rules.

# 9. Māori

There were very few differences between Māori disabled people participating in the survey and NZ Europeans.

* Eighty-six percent of Māori surveyed believed their culture was respected by their supports all or most of the time (compared with 91 percent of NZ Europeans)[[22]](#footnote-22).
* Ninety-five percent of Māori surveyed believed their spirituality or beliefs were respected by their supports all or most of the time (compared with 92 percent of NZ Europeans surveyed).

The main points of difference were in regard to work and income and home ownership:

* Ninety-four percent of working-age[[23]](#footnote-23) disabled Māori had not worked in the previous week compared with 7923 percent NZ Europeans.
* Initial review of home ownership for disabled Māori suggest four people own their own home (22 percent) in contrast to 42 percent of NZ Europeans.

# 10. What disabled people think about their lives

When thinking about the life experiences of disabled people many complex things need to be considered.

These complex things we refer to as variables. They created different sets of results for different groups. These variables included:

* Age – specifically adults versus children and young people
* Disability type
* Degree of assessed need
* Where people live and with whom
* The support package they receive.

These variables had an effect on results relating to:

* Wellbeing
* Autonomy: choice and control
* Social connectedness and relationships
* Community participation
* Development, achieving and planning
* Education, employment, living situation and income
* Satisfaction with support services.

# 11. Wellbeing

Subjective wellbeing (SWB) measures involve a number of different questions related to general happiness and other impressions.

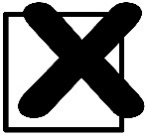
They are not questions another person (proxy respondent) can easily answer on behalf of a disabled person, so only self-report responses were used for this section.

Things that stood out for disabled people were:



**Table 4: Positive Wellbeing Indicators – self-reports only**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes/totally  Mostly | Okay/  So-so | No/never  not really |
| I trust people who are important to me | 89.4% | 8.2% | 2.4% |
| I am a happy person | 79.3% | 14.9% | 5.7% |
| I know who to ask for help, advice, or support if I need it | 81.7% | 9.8% | 8.5% |
| I love life | 82.1% | 9.5% | 8.3% |
| I am happy with my life | 74.1% | 8.2% | 17.6% |



**Table 5: Wellbeing indicators – self-reports only**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes/totally  Mostly | Okay/  So-so | No/never  not really |
| I worry about things | 48.2% | 37.6% | 14.1% |
| I believe more good things than bad things will happen to me | 58.3% | 23.6% | 18.1% |
| I am optimistic about my future | 55.3% | 26.3% | 18.4% |
| In most ways my life is close to the way I would want it to be | 56.0% | 12.0% | 32.0% |

Comparing adults with learning disabilities and adults with physical disabilities in Table 6, some variation is noted.

People with physical disabilities are:

* not as happy as people with learning disabilities
* less optimistic regarding their future
* less convinced their life is the way they want it to be.

**Table 6: People with learning and physical disabilities who self-reported on subjective wellbeing questions, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Learning Disability | Physical Disability | WMW |
| I am a happy person | 86.5 | 72.7 | 2.4\*\* |
| I know who to ask for help, advice, or support if I need it | 88.2 | 76.2 | 1.8 |
| I am optimistic about my future | 66.7 | 46.5 | 2.2\* |
| In most ways my life is close to the way I would want it to be | 82.1 | 35.7 | 4.7\*\*\* |
| I am happy with my life | 88.6 | 59.1 | 3.7\*\*\* |

\**p<*0.025, \*\**p<*0.01, \*\*\**p<*0.001

## The Cantril Ladder: A measure of Personal Wellbeing

One measure of wellbeing is the Cantril Ladder[[24]](#footnote-24). The Cantril Ladder is an international scale used in many countries and is being considered for use by the Treasury in New Zealand. It asks people to rate where they would stand on a ladder[[25]](#footnote-25), if zero represented the worst life for them and ten represented the best.

Figure 4 below indicates the range of responses on the Cantril Ladder for all disabled people who provided their own responses (self-reports). The average (or mean) for this group was 6.2 (SD 2.6) and suggests most people (77 percent) were scoring themselves at five or better.

**Figure 4: Cantril Ladder for all disabled person sample – self reports**

(vertical line=mean)

The following section concerns how Cantril Ladder measures are influenced by disability type.

## People with Physical Disability

There are variations in responses to the Cantril Ladder depending on the type of disability. For example, the range of responses for people with physical disabilities is presented in Figure 5. The average score on the Cantril Ladder for adults with physical disabilities is 5.4 (SD 2.4) compared with 7.4 (SD 2.4) for adults with intellectual disabilities[[26]](#footnote-26).

Sixty-four percent of people with physical disabilities scored themselves at five or more on the ladder compared with 91 percent of people with learning disabilities.

**Figure 5: Cantril Ladder for people with physical disabilities – self report only**

(vertical line=mean)

An examination of the results for people with physical disabilities indicates those scoring four or less on the Cantril Ladder[[27]](#footnote-27) were often people with:

* progressive conditions[[28]](#footnote-28) (40 percent) and/or
* poor health (33 percent).

When compared with people scoring five or more on the ladder, progressive conditions were indicated in 24 percent of cases and poor health in three percent.

This suggests that health plays a significant part in individual perceptions of wellbeing.

### A theme for people with physical impairments

|  |  |
| --- | --- |
|  | **A theme running through all of the results for people with physical impairments was social isolation.** |

This could be about:

* being stuck at home and being dependent on others (eg, loss of mobility and transport)
* the need to involve others to utilise the community
* losing contact with other people.

One person stated when giving a low score on the Cantril Ladder:

*I can’t get out to socialise. People who were friends have moved on.*

Another stated:

*[I] would like to see my son in [town name stated] and take my own support with me to help. [I] would like to see my grandchildren.*

Another person both grieved the loss of her independence and her changing role. When she was asked to respond to the statement, “I know who to ask for help, advice, or support if I need it”, she said:

*[I] don’t do it because I don’t want others to get involved and put in their time.*

Later she added:

*I see my family as family and to be supported. I am the Mum and [I] support them.*

When asked about her sense of belonging in the community, she stated, “I feel isolated”.

The answers to many of the questions in the survey are often linked together and complex.

For some, being visited by support workers is the only point of contact people have with others in their day. When asked what was most important to him in his life, one man said:

*Oh, to improve my life. I would love to work you know, only a few hours a day and just to have human contact. Unfortunately, my family’s not the greatest, so yeah, having human contact is a biggie to me.*

*[Interviewer]: So, you don’t see lots of people…?*

*No. If I don’t go out at all, all I see is my lady in the morning to put the sock on and the lady at night to take it off. And an hour of home help a week. That’s all I have. So, if it wasn’t for the sock…*

### What can make a difference

Table 7 indicates the differences in perceived isolation between those scoring higher on the Cantril Ladder and those scoring lower. It is clear that living alone or living with others makes a difference. People lower on the scale have fewer opportunities to connect with others (who were not support workers). Although, the rate of contact with family is similar for both groups, the rate of contact with friends is much lower for people who are scoring lower on the scale.

These results are an indication only, as the size of one group was only 15 people.

**Table 7: Social contacts and isolation questions – people with physical disabilities reporting high or low on Cantril Ladder**

|  |  |  |
| --- | --- | --- |
|  | **Scoring low on Cantril Ladder (4 or less)** | **Scoring higher on the ladder (5 or more)** |
| Live with family or friends | 26.7% | 51.7% |
| Live alone | 53.3 | 37.9 |
| Contact with friends in the last week | 35.7 | 75.0 |
| Contact with family in the last week | 78.6 | 71.4 |
|  | n=15 | n=28 |

Contrasting the two groups on other dimensions it appears that while the rate of unemployment appears similar, at 93 percent[[29]](#footnote-29), the number of people engaged in other activities is higher in the group who were scoring higher on the Cantril Ladder (13 as opposed to 26 percent for voluntary work). When people talked about voluntary activities these ranged from “knitting for the babies at the hospital” to running their own charitable trust for people with mental health issues.

Fifty percent of the people with physical disabilities, who scored higher on the scale, were engaged in further education at the time of the survey compared with 28 percent of those scoring lower on the scale.

### Social isolation

For those scoring lower on the Cantril Ladder, it is noted that 79 percent *did not* feel they had a sense of belonging in the wider community (not really or at all). This figure is almost a complete reversal of those who scored higher on the ladder with 74 percent believing they *did* have a sense of belonging all or most of the time. Again, we need to remember that one of these groups had only 15 people.

Figure 6 indicates people with physical disabilities who were scoring low on the Cantril Ladder were much less active in their communities in the two weeks prior to the survey than people scoring themselves higher on the ladder. People higher on the ladder were involved in 22 different clubs, groups and organisations[[30]](#footnote-30), compared with the four[[31]](#footnote-31) listed for people who were scoring themselves lower on the ladder[[32]](#footnote-32).

**Figure 6: Community activities in the previous two weeks, people with physical disabilities low and high on Cantril Ladder**

### Personal resources

Personal resources amongst disabled people was listed as one of the determinants in higher Social Wellbeing (SWB) scores on the Cantril Ladder scores in Europe[[33]](#footnote-33). The two features of personal resources that were most apparent were:

* social supportiveness (having people involved in your life), and
* vitality (being energised and well rested).

In our survey, one of the most common comments made by physically impaired people, scoring higher on the Cantril Ladder, was that simply being alive was sufficient to be more positive in their assessment of their life. People variously stated:

*[I’m] lucky to be alive.*

*I am, therefore I am.*

*I'm still alive.*

*[I’m] thankful I'm alive.*

*Yes. Well I’m so grateful to be still alive but it doesn’t worry which way I go because I’ve already been to heaven and back.*

The statement of “being alive” was almost used as a description of internal resourcefulness. A source of energy that kept people positive. However, for people where progressive conditions and health issues pose particular stresses that sense of inner resourcefulness can be lacking. One spouse simply commented:

*Life as she knew it is over and all she is doing is waiting to die.*

People with physical disabilities, who scored lower on the Cantril Ladder, indicate issues that need to be considered when making assessments for support:

* + where and with whom people are living (alone, with family, rest home),
  + their mobility or factors that affect their ability to move outside the home (such as transportation and the availability of people to provide support), and
  + their ability to connect with groups, places and people (this could be based on factors noted previously or their own motivational/ personal or health issues).

## People with Learning Disability and ASD

People with learning disability and ASD had a higher average score (7.1) on the Cantril Ladder than people with physical disabilities. The graph for people with learning disabilities in Figure 7 indicates a bimodal distribution (0 to 6 and 7 to 10) ie, two contrasting results. While there are some similarities with those people with physical disabilities scoring higher or lower on the ladder, there were also some unique observations. As noted previously, nearly 90 percent (89 percent[[34]](#footnote-34)) of adults with learning disabilities and ASD scored themselves 5 or higher on the Cantril Ladder. Fifty-four percent scored themselves 7 or higher.

**Figure 7: Cantril Ladder for adults with learning disabilities and ASD – self reports only**

(vertical line=mean)

People with learning disabilities and ASD who scored themselves less than seven on Cantril Ladder:

* lived alone (44 percent) compared to the upper group (25 percent[[35]](#footnote-35)). This may suggest that living with someone, even if it is in a residential service, may provide higher scores on the Cantril Ladder.
* indicated they had *few or no* friends outside of where they lived (26 percent) compared to the people rating themselves higher on the ladder (9 percent).

Sixty-two percent of the lower group had contact with friends in the previous two weeks compared with 91 percent of the upper group.

People with learning disabilities and ASD can have an impoverished circle of friends when compared with people without disabilities. It is also noted that if we did not consider other people with learning disabilities, in those friendship circles, the differences between the groups would be even larger[[36]](#footnote-36).

Seventy-seven percent of adults with learning disability and ASD, who scored themselves seven or higher on the Cantril Ladder, indicated they felt they belonged in the wider community (all or most of the time). This is in contrast to 42 percent of those who scored themselves less than seven on the ladder.

# 12. Exercising choice and control - Autonomy

## Choice with where I live and who I live with

|  |  |
| --- | --- |
|  | * **Having a choice of flatmates was rated poorly, with 37 percent of all disabled adults indicating little or no choice, and** * **72 percent of adults with learning disabilities living in residential homes indicating little or no choice.** |

Adults with learning disabilities who were living in residential homes appeared to have far less choice about who they lived with. Verbal responses to this question indicated this choice was often made by others, usually services, but on occasion whānau. For example, one person stated:

*I’m in a flatting situation…It’s a facility. My actual family chose the place where I wanted to live. So, I didn’t have any say in living here.*

Some whānau put their faith in service providers to make the right decisions, especially those who left Kimberley Centre for residential homes:

*That was decided when they left Kimberley. [They] put him in with someone he knows.*

Another person noted with to regard having a choice of flatmates:

*I’m not sure about that but the people that live with her, they’ve all been chosen so that they can get on. I mean the first thing was that they all get on together, that they will all gel. And they do, they all get on together.*

In contrast, other comments suggest the balance of personalities in community residential homes are not always positive. One person noted that choice was an evolving process but one that was dictated by the person’s behaviour or anxiety with having to live with others:

*[It] Evolved through his need... [It] took a lot of work but it’s evolved into what we see now. He's got a life.*

Those not assertive in expressing that they are not always happy about their flatmates, have developed coping mechanisms which may have evolved into normalised behaviour. For example, 18 percent of the group talked about raised anxiety in busy or noisy environments and 11 percent referred to issues with specific flatmates. However, coping with the problem tended to be the typical response:

*One or two there are a lot worse than [name of person]. He doesn't seem to mind. If he gets brassed-off he just goes into his room.*

Table 8 indicates only about a third of all adults with learning disabilities believed they had control of choosing who they lived with (all or most of the time)[[37]](#footnote-37). The difference for people with learning disabilities is in part service-based, as close to half (48 percent) live in community residential homes.

**Table 8: Responses to autonomy question: adults with learning and physical disabilities, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | All Adults | Physical Disability | Learning Disability |
| I choose who lives with me | 56.7% | 85.7% | 39.6% |

WNW=3.8, *p<*0.001, df=80, Diff in mean 1.5

### Communication

Choice can be challenging if someone has limited speech. For example, in responding to the survey item, ‘I am understood when I communicate”, 63 percent of people with learning disabilities in residential homes believed they were understood (all or most of the time)[[38]](#footnote-38).

|  |  |
| --- | --- |
|  | **Over one-third of people with learning disabilities in residential homes are not confident they are understood.** |

Often communication is thought of in terms of speech. However, people with VHNs and with limited speech are able to express their needs and desires in other ways. One proxy respondent said:

I guess if she were having a bad day and was throwing her toys out of the cot, they wouldn’t take her out.

Another proxy respondent speaking for the person (in first person) stated:

Sometimes through body language I can show what I want.

## Choice about the kind of support I get

### For people with a learning disability living in a residential home

|  |  |
| --- | --- |
|  | **77 percent did not believe they had a choice of support workers (all or most of the time)[[39]](#footnote-39),** although they did believe they knew who would be supporting them each shift. |

Also, nearly a half did not believe they:

* had much choice in the kind of support they received (56 percent)
* could make changes to their support (54 percent)
* could easily find out about the things they needed for their support (47 percent)[[40]](#footnote-40).

### Timing of support

|  |  |
| --- | --- |
|  | **For fully staffed residential homes respondents believed they had support when they needed it and at times that worked for them.** |

**Table 9: Satisfaction and adults with learning disabilities living in community residential homes (n=33 & 25)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | Yes always/Mostly | Sometimes | Not really/No |
| My support happens at the times that work for me | | 81.8% | 18.2% | 0.0% |
| My support occurs when I need it in my life | | 80.0 | 16.0 | 4.0 |
|  | **Respondents for children and young people (who typically live with whānau):**   * **did not believe supports happened at times that worked for them (26 percent: ‘not really’ or ‘not at all’), or** * **when they needed it in their life (36 percent).** | | | |

**Figure 8: Children and young people versus adults on whether support happens at times that work for the person or that it occurs when they need it in life**

|  |  |
| --- | --- |
|  |  |

It was indicated that 38 percent respondents for children and young people were less convinced (‘sometimes’ to ‘no/never’) that paid support workers received the training they needed in contrast to all adults (14 percent).

Variations in these items may be due to differences in the type of support expected and received by various groups. In particular, adults are more likely to receive supports through agencies and service providers than children and young people. In the latter case, 34 percent of all children and young people have at least some support through the carer support subsidy[[41]](#footnote-41), in contrast to 15 percent of adults.

### Having what they need

|  |  |
| --- | --- |
|  | **Over one-third of disabled people are not certain they are receiving the support they need.** |

**Table 10: Having the support I need**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | Not really/No |
| I feel the amount of support I have is right for what I need | 62.8% | 14.0% | 23.3% |

## Having positive relationships

### Friends and family: Social Interaction

|  |  |
| --- | --- |
|  | **Seventy-seven percent of all adult respondents were single at the time of the survey and only 15 percent lived with a partner or spouse.** |

Statistics in the USA indicate that 48 percent of individuals 18-29 years old are single, compared with 22 and 25 percent for two older age groups (30-49 years, 50+ years)[[42]](#footnote-42). In comparing these figures with those participating in the Baseline Study in Table 11, we found that far more people with disabilities were single in all age groups.

When considering statistics for people who were married in the US study, 58 percent of the over 50-year-olds reported being married. Only 39 percent of people with physical disabilities were married (or living with a partner) in the same age group[[43]](#footnote-43). In total[[44]](#footnote-44), only two (of 77) adults with learning disabilities reported being married[[45]](#footnote-45). Sixty-three percent of people with physical disabilities had children of their own (28 people) compared with one person with a learning disability.

**Table 11: Age by relationship status, ‘single’, all adults**

|  |  |  |  |
| --- | --- | --- | --- |
|  | All adults | Physical Disability | Learning Disability |
| 18 to 29 years | 88.0% | - | 100.0% |
| 30 to 49 years | 73.2 | - | 80.0% |
| 50+ years | 64.7 | 56.1% | 95.5% |

Missing data for people with physical disabilities is due to the small size of these subgroups.

Sixty percent of all those responding to the disabled persons survey stated they had friends outside of where they lived (yes/totally or mostly)[[46]](#footnote-46). Conversely, 31 percent said they did not have friends outside of their place of residence (‘not really’ or ‘not at all’). Figure 9 indicates adults are much more likely to suggest they have friends (63 percent) than children and young people (47 percent), mostly or totally[[47]](#footnote-47).

**Figure 9: I have friends outside of where I live (not paid staff or flatmates, etc), adults versus children and young people**

* Slightly more adults with physical disabilities (69 percent) said they had friends outside of their home (totally and mostly) than adults with learning disabilities (63 percent)[[48]](#footnote-48).
* A third of all people with learning disabilities (33 percent) indicated they did not have friends (at all or not really) in contrast to people with physical disabilities (20 percent).
* When considering people with ASD, only 50 percent believed they had friends (totally or mostly) and over a third (39 percent) believed they had few or none.

This latter finding may be a combination of the average age of the ASD group (14.3 years, SD 8.4) compared with people with learning disabilities (39.7 years, SD 19.0). Similarly, people with physical disabilities are older (average 58.8 years, SD 10.3) and many have acquired their disability later in life and therefore may have had more opportunities to develop social networks.

|  |  |
| --- | --- |
|  | **People with learning disabilities in community residential homes are less likely to indicate friendships outside their home in contrast to all other adults.** |

Adults with learning disabilities, living in community residential homes, predominantly have very high assessed needs. The level of assessed need and the character of group homes (with an average size of three people, SD 1.7) means that opportunities to meet and befriend people outside the home may be reduced as people are less likely to move around by themselves without staff support. Staffing levels may also limit opportunities for people to access the community on an individualised basis.

**Figure 10: I have friends outside of where I live (not paid staff or flatmates, etc) adults with learning disabilities in community residential homes versus all other adults**

In verbal comments, 29 percent of respondents for people in residential homes stated they had friends, but only at home or in day services. For some people in community residential groups homes, the main source of outings and social events are with people from the home or when they go to day services. When asked how often people see friends, one guardian stated:

*Honestly, I don’t know, I do know they take her out a lot, like she goes to the vocational place.*

Another guardian indicated that there were no friends outside of the home, but also stated in relation to what is important in her life:

*Oh, I think she likes going out to dinner, shows, the van rides, the train rides and to have friends.*

For some people the narrow social group of home and day services (vocational services) is valued, especially due to the long-term associations people have had with one another. As one guardian stated:

*There are four houses on the section and he goes visiting. Visiting friends in other houses.*

Yet, despite these obvious friendship links, guardians are also aware these networks may be limiting what is possible:

*I really wish [person’s name] could have a one-to-one friend… a friend he could relate to. The only thing I can think of that’s missing in his life.*

Some people stated friendships were occurring for people in community residential homes through associations with other groups or people. For example, at least two people talked about friendships that had developed through attendance at church and one stated the person “got quite friendly with the chemist lady”.

# 13. Belonging, contributing and being valued

## Community participation

The degree of community participation was surveyed using open-ended questions in the disabled persons survey. People were asked to list what community facilities they used in the previous two weeks (ie, swimming pools, parks, sports facilities, library, shopping centres etc). They were also asked whether they were members of a local group, club, marae, sports team etc. Two more questions asked were: when was the last time they went out for a meal or visited a café or pub.

**Table 12: Wording of the three community participation questions**

|  |
| --- |
| I went out for a meal in the last… (options = week, two weeks, month, more than a month, in the last year, longer than a year, never) |
| I visited a cafe or hotel (pub/bar) in the last… (options = week, two weeks, month, more than a month, in the last year, longer than a year, never) |
| What community facility(s) did I use in the last week/fortnight? |

Taking into account the combined results of the three questions in Table 12, especially with regard to people responding for the previous week to fortnight, a picture can be formed of community activity.

Results suggest that:

* Thirteen percent of all respondents indicated they did not visit community facilities or places in the previous two weeks, and
* seven percent suggested they *only* visited shopping centres[[49]](#footnote-49).

There was very little variation in these figures between adults and children or young people.

### Community involvement by disability type

Figure 11 below indicates more people with physical disability or ASD did not venture into the community when compared with people with learning disabilities. More people with physical disabilities only ventured out to the shops compared with the other two groups.

|  |  |
| --- | --- |
|  | **38 percent of all physically disabled people had limited to no community engagement in the previous two weeks.** |

This suggests that people with physical disabilities are more isolated than learning-disabled people and people with ASD.

**Figure 11: Limited or no community participation by disability type**

|  |
| --- |
|  |

### Community Involvement by support package

When considering the level of community engagement relative to the type of support provided for disabled adults in Figure 12, it is noted that people with household management and personal care support as their only form of support (HM&PC-only) were least likely to venture into the community. Given the majority of these individuals have physical disabilities, this finding is consistent with Figure 11.

|  |  |
| --- | --- |
|  | **All people associated with supported living accessed the community in the previous two weeks, although 16 percent only managed to visit shops in that time.** |

It is suggested in Figure 12 that people receiving HM&PC-only support are less likely to have community involvement than other groups.

**Figure 12: Limited to no community activities for disabled adults by type of support provided**

### Range of community activities

The range of community activities people have engaged in are presented in Figure 13. The overall results indicate visiting cafes (including pubs/bars) and restaurants in the previous two weeks was the most frequent activity, followed by shopping. Children and young people were more involved in swimming and visiting play areas and parks[[50]](#footnote-50) than adults, while adults tended to favour the library and the gym.

**Figure 13: Range of community activities in the previous two weeks, adults versus children/young people**

Figure 14 indicates the range of activities for adults with either learning or physical disabilities. The results suggest that people with learning disabilities are generally more active in the community than people with physical disabilities.

**Figure 14: Range of community activities in the previous two weeks, adults with learning or physical disabilities**

Many people in community residential homes will also attend day services for at least some of the working week. The higher level of activities in areas such as visiting parks (typically going for walks), cafes and swimming may reflect both group home and day service activities. People with supported living are typically assisted to go shopping by their support workers and the elevated result for this group may reflect that activity.

It should also be noted that the survey occurred in August and September. For some people with more fragile health, community participation may be reduced compared with activities in warmer months. Follow-up reviews of this work would need to take the time of year into account.

**Figure 15: Range of community activities in the previous two weeks by type of support**

## Membership in clubs, groups – belonging

People were asked to indicate whether they were a member of a local group, club, church, marae, sports team etc. Fewer children and young people registered membership with groups (44 percent) than adults (57 percent). Figure 16 indicates children and young people are more likely to belong to sports[[51]](#footnote-51), play and music groups[[52]](#footnote-52). Adults were more likely to belong to a church, Special Olympics[[53]](#footnote-53), sports clubs/gym[[54]](#footnote-54) and support groups[[55]](#footnote-55). ‘Other’, for adults included 29 different groups[[56]](#footnote-56) and ‘other’ for children and young people included six different groups.

**Figure 16: Membership of club or group, adults versus children and young people**

Figure 17 shows the range of groups or clubs people belong to relative to their type of support. Notably people with HM&PC-only packages are more involved in support groups and a range of smaller different groups (‘other’). This group are most likely to be people with physical impairments. Groups such as Kumbayah fellowship[[57]](#footnote-57) and Special Olympics are specifically for people with learning disabilities.

**Figure 17: Membership of club or group by support type**

# 14. Developing and achieving

## Personal development and planning

One of the principles of Enabling Good Lives is to consider the whole person when planning and delivering services. The ‘person-centred’ principle states:

Disabled people have supports that are tailored to their individual needs and goals and that take a whole-life approach rather than being split across programmes.

For some, the type of service provided appears to influence the outcomes they could hope for from disability support services. A more holistic approach may be possible for people in community residential homes and for people receiving supported living. However, services are limited in what they can achieve for people on HM&PC-only packages or for people with carer support, respite, behaviour or child development services (DHB).

In this section, personal development is considered generically, especially in terms of life or social skills. Linked to personal development is autonomy. This is people having the right to make choices with regard to their life and personal development. This is particularly important in being able to plan for and develop personal goals and aspirations.

Table 13 indicates few differences between adults and children/young people with regard to being valued for what they can already do. However, the adult group does appear less convinced they have opportunities for learning and development, their current learning or feeling supported to try new things.

**Table 13: Personal development, adults versus children, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | All adults | Children and young people | Diff in mean | WMW |
| I have opportunities for learning and development | 57.7% | 70.4% | 0.4 | 1.7 |
| The people in my life value what I can do | 83.6% | 86.7% | 0.2 | 1.3 |
| I feel supported to try new things | 63.5% | 85.3% | 0.007 | 2.1\* |
| I am learning skills to do more things | 53.4% | 72.7% | 0.7++ | 2.2\* |

\**p<*0.025, ++ Diff in mean *t*=2.9, *p<*0.01, df=76

Figure 18 shows that adults with disabilities were less convinced they were supported to try new things (see ‘sometimes’ to ‘no/never’)[[58]](#footnote-58) and many believed they were not learning skills to do more things (‘no/never’ or ‘not really’)[[59]](#footnote-59) when contrasted with children and young people.

**Figure 18: I feel supported to try new things, and learning skills to do more things, adults versus children and young people**

|  |  |
| --- | --- |
|  |  |

There were few variations between people with physical and learning disabilities except with regard to having opportunities for learning and development. In this situation, more adults with learning disabilities believed there were opportunities for learning and development (65 percent) when compared with adults with physical disabilities (55 percent).

When considering the type of support adults with disability receive, it is also important to recall that people with learning disabilities in community residential homes tend to have very high assessed needs. While, people on supported living have only high to moderate support needs (the majority also have learning disabilities). The majority of people only receiving HM&PC-only support have physical disabilities). Figure 19 indicates that those adults most likely to believe they have opportunities for learning and development are people who have supported living[[60]](#footnote-60). There is a hint in Figure 19 that level of assessed need may play a part in whether disabled people believe they have an opportunity for learning and development, based on the residential versus supported living comparison.

**Figure 19: Opportunities for learning and development by support type**

|  |  |
| --- | --- |
|  | **Eighty-two percent of learning disabled adults with high and moderate assessed need believed they had some opportunity for learning and development (all or most of the time).** |

This result compares with 42 percent of people with very high assessed needs (VHNs)[[61]](#footnote-61).

Figure 20 considers all adults with learning disabilities relative to their assessed need. What is not represented in these figures is the number of people from both groups who declined to answer this question. Fifty percent of respondents for learning disabled adults with VHNs failed to respond to this survey item (n=19 responded) and 45 percent of people with high to moderate assessed needs (n=22 responded). It is unclear why the non-response rate was this high, but perhaps for some, opportunities for personal development were not considered important, possible or relevant.

**Figure 20: Opportunities for learning and development by level of assessed need, adults with learning disabilities or their proxies**

Having opportunity to have aspirations, goals or plans in life are important to many people. One open-ended question in the disabled persons survey asked people:

If anything were possible, what are some things you would like to achieve, start doing or do more of?

The most common responses of the 115 who responded were:

* To get out more[[62]](#footnote-62) (17 people)
* Travel or have a holiday (15 people)
* Get a job, find work or open a business (adults) (11 people)
* Visit family (11 people)
* Have further education or training (8 people)
* Improve health (7 people)[[63]](#footnote-63)
* Visiting (2) or finding friends (5 people)
* Be independent or more independent, not lose independence (7 people)
* Be cured[[64]](#footnote-64) (5 people)
* Find own home, house or flat (3 people).

Then there was a long list of things that are personal goals or dreams that were not necessarily shared by many others, but which signalled where support could be invested[[65]](#footnote-65).

Table 14 indicates that children and young people are less likely to make plans based on what they are good at (all or most of the time) when compared with adults, but do appear on par with adults with regards to achieving what they want in their life albeit only around 50 percent (all or most of the time) for both groups.

**Table 14: Making plans and achieving goals, adults versus children and young people (all or most of the time)**

|  |  |  |
| --- | --- | --- |
|  | Adults (18+ years) | Children and young people |
| I can make plans based on what I want and what I'm good at | 73.6%[[66]](#footnote-66) | 33.3% |
| I am achieving the things I want in my life | 56.6% | 53.3% |
| I am encouraged to think about what I want in my life | 61.0% | 69.6% |

The difference in whether people are encouraged to think about what they want in life is highlighted in Table 14. It indicates that nearly two thirds of both groups are encouraged to think about what they want in their own life. However, more adults do not believe they are encouraged to think about what they want (23 percent) *at all or rarely*, when contrasted to children and young people (13 percent)[[67]](#footnote-67). This variation may be due to who might be encouraging people to think about their life. Most respondents for children and young people were whānau who lived with the person. Conversely, adults with disabilities live in a wider variety of settings with varying opportunities to have others encourage these questions.

**Figure 21: I am encouraged to think about what I want in my life, adults versus children and young people**

Table 15 indicates people with physical disabilities are less likely to believe they are achieving what they want in their life[[68]](#footnote-68), or feel they are encouraged to think about what they want in their life[[69]](#footnote-69). This is in comparison with adults with learning disabilities.

**Table 15: Making plans and achieving goals, adults with learning and physical disabilities, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | All Adults | Learning Disability | Physical Disability |
| I can make plans based on what I want and what I'm good at | 73.6% | 74.5% | 76.9% |
| I am achieving the things I want in my life | 56.6% | 65.7% | 46.8% |
| I am encouraged to think about what I want in my life | 61.0% | 69.0% | 54.5% |

When examining, ‘I can make plans based on what I want and what I’m good at’, some variation in responses start to occur when level of assessed need is considered.

Figure 22 indicates respondents for learning disabled adults with VHNs are less likely to believe they are able to make plans based on what they want or what they are good at, when contrasted with learning disabled adults with high and moderate levels of assessed need[[70]](#footnote-70). The number of respondents who did not provide a response to this item was higher for adults with very high assessed needs (55 percent) compared with adults with high and moderate needs (23 percent). This suggests nearly half of all possible respondents for learning disabled adults with VHNs did not consider the question was relevant, overlooked the question, didn’t understand the question or chose not to respond. Further analysis indicated all of these people resided in community residential homes.

**Figure 22: I can make plans based on what I want and what I'm good at, learning disabled adults by level of assessed need**

Figure 23 indicates that people with supported living were more likely to believe they could make plans based on what they were good at (68 percent indicating ‘yes/always’) compared with either people in community residential homes (27 percent)[[71]](#footnote-71) or people with HM&PC-only support (52 percent).

**Figure 23: I can make plans based on what I want and what I’m good at, by type of support**

Figure 24 indicates people on supported living are more likely to believe they are achieving what they want in their life. In particular, 27 percent of people with physical disabilities on HM&PC-only did not believe they were achieving the things they wanted in their own life (at all or not really), in contrast to people on supported living[[72]](#footnote-72). Similarly, 55 percent of adults with learning disabilities in residential homes did not believe they were achieving the things they wanted in their own life (all or most of the time)[[73]](#footnote-73).

**Figure 24: I am achieving the things I want in my life, by type of support**

Learning, dreaming and having ambitions or aspirations can be important ingredients to having a good life. There appears to be reduced opportunities for learning and development for adults when contrasted with children and young people. This difference may be considered a natural difference between these two groups since adults are at different stages of personal development. There appears to be differences in the opportunities for learning and development made available to adults, based primarily on level of assessed need, especially for people with learning disabilities. These differences are reflected in direct comparisons (learning disabled VHN versus all other learning-disabled adults) and the support packages they receive, which are also divided between VHNs primarily in residential services and high/moderate assessed needs in supported living.

Adults appear to have more opportunity to make plans based on what they are good at. Although, both adults and young people indicated fairly low levels of achieving what they wanted (between 57 and 53 percent respectively). All adults listed a myriad of dreams and ambitions but people with physical disabilities and those supported only by HM&PC funding did not believe they were achieving what they wanted in their own life.

# 15. Education

Fourteen percent of adults with learning disabilities and ASD had no formal schooling in their lifetime. The majority of these people were individuals who had lived at Kimberley Centre from early childhood until the Centre closed in 2006. Figure 25 shows that the highest qualification for adults with either learning disability or ASD was one person out of 86 completing the Level 4 Certificate in Human Services (through *Careerforce*)[[74]](#footnote-74). Nearly three quarters (74 percent) of all adults in the Baseline Study with learning disabilities and ASD had some high school experience but no qualifications. Twenty-seven percent stayed in school until 21 years old.

People with physical disabilities had a wider range of qualifications and educational experience. Thirteen percent held university degrees and another 13 percent attained professional qualifications (certificates and diplomas). Thirty-nine percent of people with physical disabilities had some high school education but left without a qualification.

**Figure 25: Qualifications and school experience by type of disability**

Eight percent of all adults (11 of 134) and one young person (of 5 not in school) indicated they were continuing their education. Ten of these people suggested their training was formal in the sense that a certificate or diploma would be the result[[75]](#footnote-75).

Six percent of all disabled people surveyed indicated an ambition of further training or education. When asked directly if people wanted further education, 42 percent of those who responded stated they would[[76]](#footnote-76).

|  |  |
| --- | --- |
|  | **Of the people who wanted further education, 69 percent cited barriers to pursing this.** |

One of these people had started a course but had to stop due to safety and access issues:

*I was studying Māori at the Wānanga and it was a social work first year, but what I discovered is that although they had lifts it was really hard for me to get from there down to the bus stop, and I had a fall. They had uneven concrete and when I went down, I concussed myself so I ended up in A & E and staying a few nights. But at the end of a couple of months it was clear that I didn’t, I’d missed too much, and even though my tutor had come here twice and I had all the reading material I just couldn’t quite fill in the gaps.*

Figure 26 shows finding assistance or support workers was cited as the largest barrier to pursuing further education followed closely by cost. For adults with learning disabilities and ASD the larger barrier was finding support workers to assist with access and classroom support (50 percent), while for people with physical disabilities the larger issue appeared to be the cost of courses and/or the cost of transport to the courses (4/10 people)[[77]](#footnote-77). The following dialogue outlined at least one barrier to further study:

*[Disabled person]: last week I looked at media design at Auckland. The website… [So, I’m] just like, like waiting to see if it’s the right time for it. Yeah.*

*[His mother]: There’s nothing to support [person’s name] if he went to Auckland, that’s the thing. We all know the story with the cost of living. If he could find something in the Manawatu…*

**Figure 26: Barriers to further education, all adults**

Another whānau member noted with regard to barriers:

*[Son] did want to try to do traffic control but then it was trying to find someone to sit with him and help with the book work etc. Not that many people around to sit with him 9-3. Services or people.*

## People still in school

There were four questions concerning schooling[[78]](#footnote-78). Sixty-nine percent of school students (pre-school to 21 years old) indicated they had additional supports at school besides the classroom teacher. Although most were happy with the degree of classroom support, some clearly were not. In response to this question one parent stated:

*This is a sore point at school, they’re not good at supporting these kids. He’s in the process of getting another RTLB[[79]](#footnote-79), resource teacher learning behaviour, to support the teacher around special needs kids. But he’s not getting access to a teacher’s aide at all really.*

There also appears to be concerns with how ORS[[80]](#footnote-80) funding is used in the classrooms according to some whānau, as the following dialogue suggests:

*[Mum]: So, she has obviously aides, she gets so many aid hours per week.*

*[Dad]: But I don't think the aides necessarily go specifically to her.*

*[Mum]: Well exactly because everything is pooled.*

*[Dad]: Because they pool it so basically how it works, they throw all the ORS funding in the room basically and it gets split up. That’s how it works.*

*[Mum]: Exactly so [child’s name] funding is actually helping fund kids that don't have ORS funding.*

How ORS money is used in schools can appear a little confusing to some people, while others seem to have their own grasp on how it should be working:

*I feel under the new system the education department has really been put into a position where they are becoming more accountable, or they have to be more accountable, because if it goes over a certain value then every cent has to be accounted for… Say if this kid is entitled to ten grand [then] you have to justify that ten grand. If this kid over here is fifty grand, because he’s really special needs, then that all has to be accounted for. Where my impression of what’s happening, they’ve got this money, and it just went into a big bowl and the schools spent it how they wanted to spend it, not on individual people.*

Nineteen percent of respondents indicated they had ORS funding (although this question was not asked directly) and one stated they had an intensive wraparound service (which includes ORS).

Thirty-one percent of students at school indicated they were mainly in segregated classrooms or schools; however, as one whānau suggested this does not mean completely segregated for most people:

*It’s a special unit in the mainstream school but they’re still part of mainstream they just go off certain times of the day to go do their thing. Yes, she’s still part of mainstream and she does normal class work, well if they’re doing class, she just does her work alongside, but then in the afternoon they all, the other special needs kids, come together and they do, you know, cooking or music or something like that. So, she’s mainly mainstream I would say, yep.*

Table 16 shows that most respondents were satisfied with school experiences, with less than 20 percent responding in the ‘no/not really’ range across all items.

**Table 16: School experiences of school age students (all pre-school and school students up to and including 21-year-olds)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes/always | Sometimes | No/not really |
| My supports at school help me to learn | 81.3% | 6.3% | 12.5% |
| I can participate in everything I want at school | 77.1% | 11.4% | 11.4% |
| I have friends at school | 51.4% | 31.4% | 17.1% |
| Other students at school treat me well | 81.1% | 8.1% | 10.8% |

Students currently at school have reasonably positive experiences with other young people at their school, even though they themselves may find social interaction difficult. Historically this may not have always been the case, at least seven of the adults who had completed school reported bullying (5 percent)[[81]](#footnote-81) and another six indicated they had been expelled from school.

# 16. Employment and voluntary work

|  |  |
| --- | --- |
|  | **Eighty-three percent of all disabled adults in the Baseline Study had not worked in the week prior to the survey.** |

Of the people who worked(n=22), 64 percent had worked less than 10 hours. Only two people had worked in excess of 25 hours in the previous week. Only 14 percent of those who were working were people with physical disabilities, or 2 percent of all adults in the Baseline Study. People who acquired a disability later in life may be more likely to have retired and/or ceased work due to their disability. In particular, 74 percent of people with physical disabilities gave details of a prior history of paid employment, compared with 41 percent of adults with learning disability or ASD[[82]](#footnote-82).

Slightly more women (88 percent) than men (79 percent) were not employed in the previous week, but similar numbers of those who had worked, had only worked ten hours or less (64 and 63 percent respectively).

All but one (of 18) adult Māori[[83]](#footnote-83) (94 percent) had not worked in the week prior to the survey, compared with 80 percent of NZ Europeans.

When considering dreams, aspirations and goals, nine percent of adult disabled people indicated they wanted to work. When asked directly if working was something they wanted to do (if they were not working already), 29 percent said ‘yes’ and a further 17 percent said ‘maybe’.

When asked if they could easily find help when looking for work, 38 percent of those adults who responded to this question stated they could not (at all or not really)[[84]](#footnote-84).

When all adults were asked if they were engaged in voluntary work, 22 percent indicated they were. Of this group, 86 percent worked for ten hours or fewer. Sixty-two percent of all volunteers were adults with learning disabilities or ASD, the remaining 38 percent were adults with physical disabilities.

## Finances and income

|  |  |
| --- | --- |
|  | **95 percent of disabled people were earning under $30,000 a year.** |

Given the low employment rate, the level of personal income for disabled people would be expected to be low. Unfortunately, many adults were not willing or able to provide information with regard to personal income in the survey (25 percent). Of those who did provide some information (n=86), 40 percent simply stated they were on a benefit or had the superannuation.[[85]](#footnote-85) Of those that remained, 92 percent of the stated incomes were under $30,000 per year. Combined with those who simply stated they were on a benefit or pension; 95 percent were earning under $30,000 a year.

Survey respondents living in community residential homes all indicated they either received a benefit or earned under $30,000 per year. The majority of people in residential accommodation pay the bulk of their benefit to the service with a set amount of spending money left aside each week (typically less than $80).

Excluding residential services, of the remaining disabled adults who provided useable figures (n = 42) the average and median reported income was between $10,000 and $20,000 with 3.5 percent (two people) indicating earnings over $40,000.

For people living with a spouse or partner who was earning, there could be a boost in the amount of disposable household income that could be shared. Others may have the support of other whānau to supplement their available income.

### Transportation

A few people, in both the disabled persons and whānau surveys[[86]](#footnote-86), talked about the issue of transportation. The most prominent issue concerned costs, particularly with regard to use of taxis (five people), but also simple issues such as the cost of parking. Two people talked about not knowing what they were entitled to with regard to transport costs and three others referred to not being able to use funding for transport. Two people referred to support workers not being permitted to provide any sort of transportation in their own cars. For individuals who are being supported to go shopping, this may be particularly limiting.

Other services do provide transport, and for one man who lives alone in a rural location, the once-a-week trip into town for groceries and a fish-and-chip lunch was the only time he got out in the week.

Being able to get out and about may have direct implications for social isolation or simply enjoying life outside the home. Transport issues included:

* cost: even with taxi vouchers, a return fare can be too high for many disabled people to afford
* loss of ability to drive: many people, especially those who have acquired disabilities, are no longer able to use their own vehicles
* location: some people live in small towns or rural locations where public transport options are limited
* access: some respondents noted that even where buses were available, they were not yet fully accessible
* time: two whānau indicated the time spent transporting people to places such as school or work. One parent noted early starts and up to two hours a day spent in transport.

### Equipment and modifications

Table 17 indicates a small group of people were not satisfied they were receiving all the equipment (or modifications) they needed. When asked directly, many people provided details of what equipment they wanted and for some, what equipment they needed. Educational and communication equipment often carry large price tags and need to be robust especially for younger people. Replacing or upgrading items often becomes a financial burden when they cannot be provided by Enable NZ or the MidCentral DHB. Then some people talked about delays, for example, one man was waiting for his prosthetic leg, and another had been waiting three months for an assessment for a ramp and handrail. Another person said:

*I need equipment to get in and out of bed (just had rails). Enable sent a letter to hospital – hospital replied they were short of staff and would get there at some point. This was 3-4 months ago.*

Rules governing what can be funded may also complicate some situations. One man noted he needed a ramp to get in and out of his house and had applied to have one installed. However, while he was waiting, he had made his own ramp to the back door and was then told he could not be funded for a new ramp because the one he made was sufficient. What he had been really needing was a ramp to his front door.

**Table 17: I have all the equipment I need**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes/totally Mostly | Somewhat | No/Not really |
| Learning Disabled (adults) | 89.5% | 2.6% | 7.9% |
| Physically Disabled | 70.5% | 6.8% | 22.7% |
| All Adults | 78.4% | 4.5% | 17.0% |
| Children and young people | 66.7% | 14.3% | 19.0% |

### Living situation and financial situation

Currently, more adults with learning disabilities reside in residential accommodation or with whānau (78 percent in total), and more adults with physical disabilities live with a spouse/partner or alone[[87]](#footnote-87) (75 percent in total).

Table 18 shows that adults with learning disability or ASD had lower rates of home ownership than people with physical disabilities. Excluding people who live with family/whānau or those in residential homes the number of adults with learning disabilities or ASD who own their own home reduced to two people.

Initial review of home ownership for disabled Māori suggest four people own their own home (22 percent) in contrast to 42 percent of NZ Europeans. The sample size was too small to break these figures down further (ie, by disability type).

**Table 18: Home ownership by disability type and ethnicity (adults only)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Learning disability/ASD | Physical disability | Māori | NZ European | All adults |
| I own my own home | 12.9% | 58.3% | 22.2% | 42.0% | 29.3% |

A recurring concern related to the disabled person’s financial situation and not being able to afford to pay for things. This ranged from visiting dentists or other health professionals to transport[[88]](#footnote-88). For example, one man stated he could not go out into the community:

*It’s not happening due to finances and health. I can't go out. Can't remember the last time I had a good dinner… I would like to join the Cossie Club. I would like to join the 'four stroke club'. I don't have the money to get there every Tuesday. Gas money and stuff.*

Eighteen percent of people with physical disabilities referred to costs or financial concerns.

The man from the example above went on to state:

*I didn’t realise you had to be rich to be ill or injured.*

# 17. What disabled people think about disability support services

There were 26 Likert Scale items specifically related to how people experience disability support. Satisfaction was considered as agreement with the two highest ratings on the five-point Likert Scale (‘yes/always’ and ‘mostly’). Taken together these items have an average satisfaction rating of 66 percent across all 26 questions (SD 17 percent). However, as noted in earlier sections, caution is needed when clumping together questions with potentially different constructs. A review of individual items is important.

For initial comparison purposes, 14 survey items that focused on how disability supports assist individuals are presented in Table 19.

**Table 19: Fourteen survey items that focus on how disability supports services assist individuals, as an overall view of satisfaction**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | not really/no |
| Supports help me pursue my own interests | 62.9% | 17.9% | 19.2% |
| I know who will be supporting me each day/shift | 77.8% | 9.6% | 12.6% |
| My supports help me connect to people and places that are important to me | 65.2% | 14.5% | 20.3% |
| My support happens at the times that work for me | 76.6% | 12.7% | 10.8% |
| I have enough support to achieve what I want | 67.1% | 14.8% | 18.1% |
| My support hours can be flexible | 65.9% | 14.3% | 19.8% |
| My support occurs when I need it in my life | 78.5% | 10.0% | 11.5% |
| My paid workers understand how to support me safely | 92.4% | 5.5% | 2.1% |
| My paid workers receive the training they need | 82.6% | 9.6% | 7.8% |
| I am supported to maintain and improve my health | 84.0% | 6.4% | 9.6% |
| I feel supported to try new things | 68.5% | 17.4% | 14.1% |
| I am supported to be actively involved in my homelife | 74.8% | 16.1% | 9.0% |
| I feel the amount of support I have is right for what I need | 62.8% | 14.0% | 23.3% |
| I think the money I get for my support is well spent | 73.3% | 9.2% | 17.5% |

The satisfaction rating for these 14 questions raised the average satisfaction to 74 percent (SD 9 percent, CI 0.05[[89]](#footnote-89)). A similar trend in responses were noted when people with learning disabilities (adults, children and young people) were considered separately. For this group the average satisfaction over the 14 survey items was 77 percent (SD 9 percent). Average satisfaction across all 14 survey items for people with physical disabilities was 72 percent (SD 11 percent). Three survey items scored lower for adults with physical disability when contrasted with adults with learning disabilities.

Figure 27 indicates people with physical disabilities are less likely to believe that supports assist them to pursue their own interests when compared with adults with learning disabilities[[90]](#footnote-90). While not significant overall, this item does indicate 28 percent of people with physical disabilities did not believe (at all or not really) that supports helped them pursue their own interests in contrast to 2 percent of adults with learning disabilities. However, as noted previously, most of the people with physical disability receive only HM&PC-only, which are not contracted to provide support for community integration.

**Figure 27: ‘Supports help me to pursue my own interests’, by** **adults with learning or physical disabilities[[91]](#footnote-91)**

Figure 28 shows fewer physically disabled people believed supports connected them with people and places that were important to them than adults with learning disabilities. The overall trend in this item was not statistically significant between the two groups, but 38 percent of people with physical disabilities did not believe (not really or at all) that supports helped them connect with people and places that were important to them, in contrast to eight percent of adults with learning disabilities.

**Figure 28: ‘Supports help me connect to people and places that are important to me’, by adults with learning or physical disabilities**

Figure 29 indicates 46 percent of people with physical disabilities were less certain (‘sometimes’ to ‘no/never’) that the amount of support provided was right for what they needed, compared with 21 percent of adults with learning disabilities[[92]](#footnote-92).

**Figure 29: 'I feel the amount of support I have is right for what I need', by adults with learning or physical disabilities**

While these initial differences in satisfaction between adults with learning and physical disabilities were not strong, they add the clues of a more complex picture for both of these groups. It also raises questions regarding satisfaction among other subgroups within the overall sample.

## Satisfaction for people with Autism Spectrum Disorder (ASD), Children and Young Adults

Overall, for people with Autism Spectrum Disorder (ASD), people were less satisfied with their support services across six of the 14 survey items in contrast to overall results, although sample size in for some of these items was quite small and should be read with caution (mean 65 percent, SD 15 percent). The difference between this group and those with learning and physical disabilities appears to be related to the different age distribution of the groups.

**Table 20: Fourteen survey items indicating satisfaction with disability support services for all ASD respondents**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | not really/no | n |
| Supports help me pursue my own interests | 48.0% | 12.0% | 40.0% | 25 |
| I know who will be supporting me each day/shift | 77.3% | 4.5% | 18.2% | 22 |
| My supports help me connect to people and places that are important to me | 59.1% | 18.2% | 22.7% | 22 |
| My support happens at the times that work for me | 52.0% | 28.0% | 20.0% | 25 |
| I have enough support to achieve what I want | 42.3% | 19.2% | 38.5% | 26 |
| My support hours can be flexible | 61.9% | 14.3% | 23.8% | 21 |
| My support occurs when I need it in my life | 65.0% | 10.0% | 25.0% | 21 |
| My paid workers understand how to support me safely | 88.9% | 0.0% | 11.1% | 18 |
| My paid workers receive the training they need | 60.0% | 20.0% | 20.0% | 15 |
| I am supported to maintain and improve my health | 86.7% | 3.3% | 10.0% | 30 |
| I feel supported to try new things | 86.2% | 10.3% | 3.4% | 29 |
| I am supported to be actively involved in my homelife | 67.9% | 28.6% | 3.6% | 28 |
| I feel the amount of support I have is right for what I need | 50.0% | 5.0% | 45.0% | 20 |
| I think the money I get for my support is well spent | 73.7% | 0.0% | 26.3% | 19 |

Table 21 indicates respondents for all children and young people[[93]](#footnote-93) (including both learning disabled and ASD) were generally less satisfied with services than adult respondents.

**Table 21: Fourteen survey items indicating satisfaction with disability support services, all children and young people and adults, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | All Children and young people | All adult | Difference in mean | WMW |
| Supports help me pursue my own interests | **37.9%** | 68.9 | 0.9 | 3.2\*\*\* |
| I know who will be supporting me each day/shift | 83.3% | 76.6% | 0.09 | 0.4 |
| My supports help me connect to people and places that are important to me | 55.6% | 67.6% | 1.0 | 1.0 |
| My support happens at the times that work for me | **51.6%** | 82.7% | 0.7 | 2.7\*\* |
| I have enough support to achieve what I want | **36.7%** | 74.4% | 1.1 | 3.8\*\*\* |
| My support hours can be flexible | 60.9% | 67.0% | 0.4 | 0.9 |
| My support occurs when I need it in my life | **59.1%** | 82.4% | 0.8 | 2.0\* |
| My paid workers understand how to support me safely | 95.7% | 91.8% | 0.05 | 0.4 |
| My paid workers receive the training they need | **62.5%** | 85.9% | 0.7 | 2.5\*\* |
| I am supported to maintain and improve my health | 86.1% | 83.3% | 0.03 | 0.4 |
| I feel supported to try new things | 85.3% | 63.8% | 0.5 | 2.1\* |
| I am supported to be actively involved in my homelife | 69.7% | 76.2% | 0.04 | 0.2 |
| I feel the amount of support I have is right for what I need | **41.7%** | 67.6% | 1.1 | 2.7\*\* |
| I think the money I get for my support is well spent | 65.4% | 75.5% | 0.5 | 1.2 |

\**p<*0.025*,* \*\**p<*0.01, \*\*\**p<*0.001

The highlighted (and statistically significant) survey items in Table 21 suggest that only around one-third of respondents for children and young people believed they had enough support either to achieve what they wanted or found supports being right for what they needed. Only a third believed supports enabled them to pursue their own interests. Overall, the average satisfaction level for all of these items is lower (64 percent, SD 19 percent) in contrast to all adults surveyed (mean 76 percent, SD 8 percent).

Figure 30 indicates the range of differences between adults and children/young people on whether they believed they had sufficient services to achieve what they wanted or enough support for what they needed. In both cases respondents for children and young people tended to respond negatively to these questions. In particular:

|  |  |
| --- | --- |
|  | **Forty-two percent of respondents for children and young people did not believe, at all, that the amount of support provided was right for what they needed.** |

**Figure 30: Children and young people versus adults on satisfaction on whether they have sufficient services**

|  |  |
| --- | --- |
|  |  |

Figure 31 shows that only 38 percent of respondents for children and young people believed supports enabled them to pursue their own interests (1.1), all or most of the time, in contrast to 69 percent of all adults.

**Figure 31: Adults versus children and young people on whether they believe supports assist them to pursue their own interests**

|  |
| --- |
|  |

The variation in satisfaction noted in this section and the variation noted between different people based on disability type, suggest that blanket statements concerning satisfaction for whole populations may be misleading.

## Satisfaction with supports and autonomy

Autonomy concerns how much choice or control a person experiences in their own life. The section, in the disabled persons survey, that examined autonomy had several questions related to the individuals’ experience of the disability support system. For example, ‘whether a person has a choice of who lives with them’.

Previously we considered autonomy in terms of life choices such as where and with whom people lived. However, taking into account all of the autonomy questions in Table 22 many are directly relevant to services or supports.

Table 22 indicates differences in perceived autonomy across a number of questions for adults who have learning versus physical disabilities. This raises questions about how satisfaction and autonomy may vary between other groups.

**Table 22: Responses to autonomy questions: adults with learning and physical disabilities, (‘yes/always’ and ‘mostly’)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | All Adults | Physical Disability | Learning Disability |
| I can easily find out about the things I need for my support | 62.5% | 72.7% | 54.3% |
| I can make changes to my supports if I need to | 60.7% | 65.9% | 59.1% |
| I choose what happens in my life | 63.8% | 69.6% | 61.9% |
| I have help to make choices if I need/want it | 78.9% | 74.4% | 82.5% |
| I can choose who my support staff will be | 44.9% | 58.7% | 36.4% |
| I know who will be supporting me each day/shift | 76.6% | 76.7% | 75.8% |
| I choose who lives with me | 56.7% | 85.7% | 39.6% |
| I have choices about the kind of support I receive | 53.1% | 59.5% | 53.2% |
| I choose what happens in my day | 67.7% | 79.2% | 63.9% |
| I can make plans based on what I want and what I'm good at | 73.6% | 76.9% | 74.5% |
| I am achieving the things I want in my life | 56.6% | 46.8%[[94]](#footnote-94) | 65.7% |
| I decide when to share my personal information | 78.9% | 90.2% | 70.5%[[95]](#footnote-95) |

## Satisfaction, autonomy and type of support

### Satisfaction, autonomy and community residential homes

Table 23 indicates, that for the most part, respondents for adults with learning disabilities living in community residential homes were satisfied with services across a number of indicators (n=38).

**Table 23: Satisfaction and adults with learning disabilities living in community residential homes**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | not really/no |
| Supports help me pursue my own interests | 78.1% | 15.6% | 6.3% |
| I know who will be supporting me each day/shift | 60.7% | 14.3% | 25.0% |
| My supports help me connect to people and places that are important to me | 78.1% | 12.5% | 9.4% |
| My support happens at the times that work for me | 81.8% | 18.2% | 0.0% |
| I have enough support to achieve what I want | 81.3% | 18.8% | 0.0% |
| My support hours can be flexible | 46.7% | 26.7% | 26.7% |
| My support occurs when I need it in my life | 80.0% | 16.0% | 4.0% |
| My paid workers understand how to support me safely | 97.1% | 2.9% | 0.0% |
| My paid workers receive the training they need | 90.3% | 9.7% | 0.0% |
| I am supported to maintain and improve my health | 91.2% | 5.9% | 2.9% |
| I feel supported to try new things | 55.2% | 27.6% | 17.2% |
| I am supported to be actively involved in my homelife | 70.6% | 20.6% | 8.8% |
| I feel the amount of support I have is right for what I need | 85.0% | 5.0% | 10.0% |
| I think the money I get for my support is well spent | 81.3% | 12.5% | 6.3% |

When asked in open-ended questions what they liked about the supports that were provided:

* nearly a third referred to satisfaction with support workers[[96]](#footnote-96) (34 percent),
* how well they were kept busy or active (37 percent)[[97]](#footnote-97).

Other respondents suggested they were happy with ‘everything’ or the individual was simply ‘happy’ or ‘content’ (29 percent).

When asked what people did not like about their supports or what they wanted to change (or start doing or do more of in their life)[[98]](#footnote-98), 24 percent stated they wanted to get out more, be less bored or be more active.

Table 24 indicates the majority of items had low levels of autonomy for people with learning disabilities living in community residential homes.

|  |  |
| --- | --- |
|  | **Only about a third of people with learning disabilities living in community residential homes believed they could make decisions in their life, or about what happens with their day[[99]](#footnote-99).** |

Similarly Table 25 indicates only about a third of respondents for adults with VHNs believed they could make decisions about what happened in their life (34 percent) and 42 percent indicated they could make decisions about what happened in their day.

Routine is often seen as positive, even necessary, especially for people who become anxious around change. However, many people in residential homes were expected to conform to a routine that is more about what others want, rather than the person. For example, after some struggles with day services one person is now looking for a routine that is personalised to herself and her choices:

*If [she] doesn't want to go to day base they won't force her. They will either take her back home or find alternative option for the day.*

However, for many, fitting-in with the routine of others is the norm. As these respondents noted:

*[Choice was] limited because of where he lives and the day base activities.*

And

She’s part of the routine of the house.

**Table 24: Responses to autonomy questions: Adults with learning disabilities in community residential services**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | No/Not really |
| I can easily find out about the things I need for my support | 46.7% | 6.7% | 46.7% |
| I can make changes to my supports if I need to | 30.8% | 15.4% | 53.8% |
| I choose what happens in my life | 36.7% | 33.3% | 30.0% |
| I have help to make choices if I need/want it | 75.9% | 10.3% | 13.8% |
| I can choose who my support staff will be | 12.9% | 9.7% | 77.4% |
| I know who will be supporting me each day/shift | 60.7% | 14.3% | 25.0% |
| I choose who lives with me | 13.8% | 13.8% | 72.4% |
| I have choices about the kind of support I receive | 33.3% | 11.1% | 55.6% |
| I choose what happens in my day | 38.2% | 35.3% | 26.5% |
| I can make plans based on what I want and what I'm good at | 46.7% | 26.7% | 26.7% |
| I am achieving the things I want in my life | 55.2% | 27.6% | 17.2% |
| I decide when to share my personal information | 50.0% | 7.1% | 42.9% |

How satisfied people living in community residential homes were with the disability support system is complex. Adults with learning disabilities in residential homes were older on average (46 years, SD 14) and had a higher assessed level of need (90 percent VHN) than other adults with learning disabilities in this Baseline Study (who have an average age 40, SD 14, with 10 percent assessed as VHN). They were also more likely to have a proxy respondent (74 percent[[100]](#footnote-100) compared with 33 percent for all other adults in the Baseline Study).

|  |
| --- |
| Assuming proxy respondents are making an effort to answer the survey items from the perspective of the person (rather than themselves), then the picture painted is one of apparent satisfaction with services, **except where personal autonomy is concerned.** |

If we assume proxy respondents believe adults with VHNs have limited ability to make choices, the view they are not often able to have a choice in flatmates or staff is concerning. Likewise, the view that only a third have a choice of what happens in their life, or even on a daily basis, paints a picture of a group of people who are controlled by others.

**Table 25: Responses to autonomy questions, VHNs versus high and moderate needs, all people with VHNs (‘yes/always’ and ‘mostly’).**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | VHNs | High/Moderate  needs | Diff in mean | WMW |
| I can easily find out about the things I need for my support | 47.1 | 70.3 | 0.9+ | 2.0\*\* |
| I can make changes to my supports if I need to | 34.5 | 72.1 | 0.5+ | 2.3\*\*\* |
| I choose what happens in my life | 34.0 | 85.3 | 1.4+++ | 4.8\* |
| I have help to make choices if I need/want it | 72.0 | 84.8 | 0.7++ | 2.4\*\* |
| I can choose who my support staff will be | 30.8 | 55.9 | 1.5+++ | 4.0\*\*\* |
| I know who will be supporting me each day/shift | 62.5 | 87.7 | 1.0+++ | 3.5\*\*\* |
| I choose who lives with me | 25.0 | 85.4 | 2.5+++ | 4.6\*\*\* |
| I have choices about the kind of support I receive | 32.4 | 65.1 | 1.2++ | 2.8\* |
| I choose what happens in my day | 41.8 | 86.5 | 1.4+++ | 5.3\*\*\* |
| I can make plans based on what I want and what I'm good at | 48.4 | 85.5 | 1.1++ | 2.7\* |
| I am achieving the things I want in my life | 42.9 | 64.0 | 0.8+++ | 3.1\*\*\* |
| I decide when to share my personal information | 60.0 | 88.5 | 1.4++ | 3.3\*\*\* |

\**p<*0.025*,* \*\**p<*0.01, \*\*\**p<*0.001. Differences in mean for student *t,* +*p<*0.025*,* ++*p<*0.01, +++*p<*0.001.

## Satisfaction, autonomy and supported living

|  |  |
| --- | --- |
|  | **People receiving supported living appear very satisfied with services over most of the survey items in Table 26 (average 81 percent, SD 9 percent).** |

When asked what people liked about their support two thirds (66 percent) mentioned their relationship with their support workers. One person stated:

*What I like is … if they have any problems they ring and let me know, if they can’t make it, and they’re always good to talk to, good to get on with. Yes. My carer’s a lovely lady who is very friendly and very nice, very nice and friendly.*

When asked what they did not like about their support or what they wanted to change the same number stated that there was nothing they did not like or wanted to change.

Positive comments regarding the flexibility of support hours focused on a willingness of support workers to fit in around the individual as much as possible, but with an understanding that the support worker also had other people they visited. There were few long answer statements about flexibility, but those that were available were generally positive. One person stated:

*They are flexible they can work around what days you want to do and they’re there to do what you want to do, it’s not about them. It’s about me.*

In one service people had noted they can bank their support hours if they will be absent on a particular day and they provide enough notice.

One father talked about his general satisfaction with the supported living service for his son:

*Every time [wife’s name] and I’ve gone to meetings the information that we go hunting for on behalf [of our son] has all been free flowing and it comes across. They go out of their way to try and say, ‘okay this is one option, that’s another option, this is another option. But with the funding we suggest this option’, if you know what I mean. The people that we talk to [at the service] are brilliant.*

**Table 26: Satisfaction, supported living (n=25)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | not really/no |
| Supports help me pursue my own interests | 76.0% | 24.0% | 0.0% |
| I know who will be supporting me each day/shift | 87.5% | 8.3% | 4.2% |
| My supports help me connect to people and places that are important to me | 75.0% | 15.0% | 10.0% |
| My support happens at the times that work for me | 76.0% | 8.0% | 16.0% |
| I have enough support to achieve what I want | 91.3% | 4.3% | 4.3% |
| My support hours can be flexible | 70.8% | 25.0% | 4.2% |
| My support occurs when I need it in my life | 86.4% | 9.1% | 4.5% |
| My paid workers understand how to support me safely | 87.0% | 8.7% | 4.3% |
| My paid workers receive the training they need | 94.7% | 0.0% | 5.3% |
| I am supported to maintain and improve my health | 86.4% | 13.6% | 0.0% |
| I feel supported to try new things | 72.0% | 16.0% | 12.0% |
| I am supported to be actively involved in my homelife | 91.3% | 8.7% | 0.0% |
| I feel the amount of support I have is right for what I need | 73.9% | 13.0% | 13.0% |
| I think the money I get for my support is well spent | 69.6% | 13.0% | 17.4% |

The more striking difference between people who use supported living as opposed to community residential homes (see Table 27) is with reference to autonomy.

Table 27 indicates positive responses on all indicators with the exception of, ‘choice of support worker’. Most people on supported living may be introduced to a support worker who had already been assigned to work with them. However, if the match between the person and the support worker does not appear to work well, then the individual is generally able to suggest they want a change.

**Table 27: Autonomy, supported living, (all or most of the time) compared to residential (learning disabled)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Supported living | Residential (learning disability) | Diff in mean | WMW |
| I can easily find out about the things I need for my support | 80.0% | 46.7% | 1.5 | 3.0\*\*\* |
| I can make changes to my supports if I need to | 95.2% | 30.8% | 2.0 | 3.8\*\*\* |
| I choose what happens in my life | 90.9% | 36.7% | 1.5 | 4.6\*\*\* |
| I have help to make choices if I need/want it | 95.8% | 75.9% | 0.8 | 2.6\*\* |
| I can choose who my support staff will be | 60.9% | 12.9% | 1.8 | 4.4\*\*\* |
| I know who will be supporting me each day/shift | 87.5% | 60.7% | 1.1 | 3.2\*\*\* |
| I choose who lives with me | 83.3% | 13.8% | 2.6 | 4.4\*\*\* |
| I have choices about the kind of support I receive | 75.0% | 33.3% | 1.6 | 3.5\*\*\* |
| I choose what happens in my day | 100.0% | 38.2% | 1.7 | 5.5\*\*\* |
| I can make plans based on what I want and what I'm good at | 90.9% | 46.7% | 1.3 | 3.4\*\*\* |
| I am achieving the things I want in my life | 69.6% | 55.2% | 0.6 | 1.9 |
| I decide when to share my personal information | 90.9% | 50.0% | 1.5 | 3.7\*\*\* |
|  | n=25 | n=38 |  |  |

\**p<*0.025*,* \*\**p<*0.01, \*\*\**p<*0.001.

For the most part, people with supported living were very satisfied with the services they received[[101]](#footnote-101) and believed those services helped them stay connected with friends and the community[[102]](#footnote-102). Unlike those individuals in community residential homes, people who have supported living indicated they had a great deal of control over their daily lives. None of those in supported living[[103]](#footnote-103) believed they did not have control of their own lives to some extent. This contrasts with 84 percent of people in residential services indicating (via proxy respondents) they had no or little control of their own life.

## Household management & personal care (HM&PC) only, satisfaction and autonomy

Table 28 indicates that for the most part, people with physical disabilities receiving HM&PC support only were satisfied with the services they received across most of the 14 satisfaction indicators. The two notable exceptions involve whether supports helped the person to pursue their own interests and whether supports assist the person to connect with people and places that are important to them.

**Table 28: Satisfaction, people with physical disabilities receiving HM&PC support only, (n=31).**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes always/Mostly | Sometimes | not really/no |
| Supports help me pursue my own interests | 50.0% | 15.4% | 34.6% |
| I know who will be supporting me each day/shift | 78.6% | 17.9% | 3.6% |
| My supports help me connect to people and places that are important to me | 39.1% | 4.3% | 56.5% |
| My support happens at the times that work for me | 86.7% | 10.0% | 3.3% |
| I have enough support to achieve what I want | 71.0% | 12.9% | 16.1% |
| My support hours can be flexible | 73.3% | 6.7% | 20.0% |
| My support occurs when I need it in my life | 85.7% | 10.7% | 3.6% |
| My paid workers understand how to support me safely | 100.0% | 0.0% | 0.0% |
| My paid workers receive the training they need | 91.7% | 4.2% | 4.2% |
| I am supported to maintain and improve my health | 72.4% | 3.4% | 24.1% |
| I feel supported to try new things | 72.0% | 12.0% | 16.0% |
| I am supported to be actively involved in my homelife | 78.6% | 14.3% | 7.1% |
| I feel the amount of support I have is right for what I need | 60.0% | 16.7% | 23.3% |
| I think the money I get for my support is well spent | 70.8% | 4.2% | 25.0% |

We compared the response differences between adults with learning and physical disabilities for both of these survey items. We note people with physical disabilities were less likely to believe they were enabled to pursue their own interests or connect with people and places that are important to them. Figure 32 suggests that differences may be associated with the type of support provided. People only receiving HM&PC support appeared less likely to experience support that enabled them to pursue their own interests[[104]](#footnote-104) or connect them with people and places that were important to them[[105]](#footnote-105) when compared to people with supported living[[106]](#footnote-106).

**Figure 32: People with physical disabilities receiving HM&PC support only and people on supported living**

|  |  |
| --- | --- |
|  |  |

Table 29 outlines perceptions of autonomy for people with physical disabilities on HM&PC funding only, in contrast to adults on supported living. In general, people on supported living tend to be more positive about the degree of autonomy they believe they experienced, although less than a third of both groups believed they have complete control over decisions regarding support staff. People on HM&PC funding were also less certain they had control over what kind of support they received and whether they felt they could make changes to their supports.

**Table 29: Autonomy, people with physical disabilities receiving HM&PC support only and people on supported living, all or most of the time**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | HM&PC only (physical disability) | Supported living | Diff in mean | WMW |
| I can easily find out about the things I need for my support | 75.0% | 80.0% | 0.3 | 1.3 |
| I can make changes to my supports if I need to | 65.4% | 95.2% | 0.7++ | 2.1\* |
| I choose what happens in my life | 70.0% | 90.9% | 0.6+ | 1.5 |
| I have help to make choices if I need/want it | 71.4% | 95.8% | 0.7++ | 1.8 |
| I can choose who my support staff will be | 60.0% | 60.9% | 0.3 | 0.5 |
| I know who will be supporting me each day/shift | 78.6% | 87.5% | 0.3 | 1.3 |
| I choose who lives with me | 95.5% | 83.3% | 0.2 | 0.7 |
| I have choices about the kind of support I receive | 59.3% | 75.0% | 0.5 | 1.4 |
| I choose what happens in my day | 80.6% | 100.0% | 0.6++ | 2.5\*\* |
| I can make plans based on what I want and what I'm good at | 76.9% | 90.9% | 0.3 | 1.2 |
| I am achieving the things I want in my life | 43.3% | 69.6% | 0.8++ | 2.6\*\* |
| I decide when to share my personal information | 92.6% | 90.9% | 0.09 | 0.1 |

\**p<*0.025*,* \*\**p<*0.01, \*\*\**p<*0.001. Differences in mean for student *t,* +*p<*0.025*,* ++*p<*0.01, +++*p<*0.001.

Figure 33 indicates 27 percent of physically disabled people who only receive HM&PC support did not believe (at all or not really) they are achieving the things they want in their own life, in contrast to 4 percent of people on supported living.

While this survey item does not focus on disability supports per se, it may suggest supports are not focused on anything other than household management and personal care support. On the other hand, having these supports may provide people with more time to focus on things that are important to them. For example, in response to the question ‘supports help me pursue my own interests’ (item 1.1) one person stated:

*Well I think I would say that the Aqua Rehab has freed me up. But then I have only put that down as a club not as a service or a support. Yes [my support worker] does free me up because I can do things while she’s doing things. I just don’t, I can’t, vacuum any more.*

**Figure 33: Achieving the things they want in their life: people with physical disabilities receiving HM&PC support and people with supported living**

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People receiving HM&PC-only support typically use agencies who provide support workers. In most cases, the agencies will introduce new support workers and people do indicate they can change support workers if they wish. However, it is not always easy for people to speak up about support workers that do not suit them and in some cases, people appear ambivalent. For example, the spouse of one disabled person stated with regard to their support worker:

*She’s good – we get on well. She’s somewhat demanding but she does achieve a purpose*.

Another person noted:

*Sometimes [my] caregiver gets a little personal. Like they are trying to control your life… or they think they are trying to make it easier for you. [You] feel like you’re losing your independence…[I] just feel uncomfortable sometimes. But at the end of each day I say ‘thank you very much for your help’.*

For other people the delay in asking for a change in support workers can leave a lasting impression, or even the last relieving support worker who was not known to the person:

*It sort of made me degraded. And she was forcing me, I said if I don't want a shower tonight, I’m not having it… she was bossy and I didn’t even know her.*

Over a third of physically disabled people on HM&PC-only support indicated they had very little or no choice in choosing support workers (37 percent)[[107]](#footnote-107). This response may be related to not being involved in choosing who was initially introduced as their support worker, rather than having a right to refuse the person. If having the right to refuse is seen as a ‘choice in support workers’ then the range of options in support worker is only related to the one person being introduced. As one person said with regard to having a choice in support workers:

*I don’t know if that’s applicable really. I’m not sure because we live in [a small town]. I’m not actually sure if we can do that because… I don't think there are many.*

While we did not ask people to indicate whether they liked their support workers directly in the disabled persons survey, 40 percent[[108]](#footnote-108) volunteered this information when asked in open ended questions what they liked about their support. One person said with regard her support worker:

*She’s quite switched on. And she’s always careful so that’s really good and at times, between three and five, she assists in meal preparation too. So that’s great.*

Another stated:

*I have amazing home help – great to have someone to aid when things are bad.*

Another thing people with physical disabilities on HM&PC-only liked about their support was the fact that they got the jobs that needed doing completed (40 percent).

When asked what physically disabled people on HM&PC funding did not like or would like to change about their support:

* twenty-three percent indicated that they would either like more hours (10 percent) or they had lost support hours or had them re-assigned to other tasks (13 percent),
* nineteen percent indicated some issues with support workers, and
* twenty-three percent talked about a lack of flexibility (either in what support workers can or cannot do, the time of day they were assigned or issues about how funding could be used).

# 18. Visual summary and conclusions

Mostly Proxy respondents

Less satisfied with services overall and are **less likely to believe they**

* have sufficient support
* are enabled to plan for or pursue own interests
* achieving what they want in their own life
* are supported to connect with people and places that are important
* are supported at times that work for them.

Mixed proxy and self-respondents

More satisfied with services overall

However, these results are dependent on disability type and type of support

See next page

HM&PC

only

Supported

living

Residential

homes

Higher satisfaction with services overall

**BUT**

Poor autonomy

Higher community participation but smaller friendship network

* Usually access community in groups

High satisfaction with services overall

Perceived reasonable autonomy

Good community participation and wider friendship network

Less satisfaction with services overall

* Less likely to achieve what they want
* Less planning towards what they want
* Less choice in kind of support

More socially isolated, can be associated with

* Disabling conditions and health
* Transport or mobility and support

Poorer perceived sense of wellbeing

The results of the disabled persons survey were complex. They needed to consider a range of variables (factors) within and between various groups.

Differences between adults and children/young people may be influenced by the type of support received. Children and young people tend to receive at home support and for this reason involved whānau and other carers. The whānau survey highlights the complexity of support for younger people in much more detail and should be referred to at the same time as this survey. Overall, there is less satisfaction with services for children and young people. This is emphasised, in particular, when whānau caring for people in their own home is considered in the whānau survey.

For adults, the complexity involves consideration of the degree of assessed need and the type of services received. It is clear that people with very high support needs, who live in residential homes, have less control over their life than any other group. This is regardless of perceived satisfaction with services. Also, people with physical impairments may receive a narrower range of support options that may not include assistance with community participation, social connectedness, or personalised planning. People with physical disabilities may also be affected by their type of disability (for example, progressive conditions) and perceived personal health.

Disabled people in general were also **limited** in terms of their:

* employment
* education prospects
* income
* relationships and
* with regard to their sense of what they wanted to achieve in their lives.

Supports, prior to the implementation of Mana Whaikaha, did not appear to assist people to overcome many of the barriers faced by disabled people. For this reason, “the system” did not seem responsive to the main tenants of the New Zealand Disability Strategy or Enabling Good Lives.

# 19. What now

## Other things to read

* Baseline Study of the Disability Support System in the

MidCentral Area: Summary Report

* Baseline Study of the Disability Support System in the

MidCentral Area: Whānau Report

* Baseline Study of the Disability Support System in the

MidCentral Area: Survey Tools

# 20. Glossary of abbreviations and terms

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| |  |  |  | | --- | --- | --- | | ASD | Autism spectrum disorder | | | CDS | Child Development Service (provided through the MidCentral DHB) | | | DPO | Disabled persons organisation | | | DSS | Disability Support Services | | | Enable New Zealand | Enable was the NASC in MidCentral area before the implementation of Mana Whaikaha | | | EGL | Enabling Good Lives | | | IDI | Integrated Data Infrastructure | | | IF | Individualised funding | | | Learning disability | This is the term preferred by People First rather than ‘intellectual disability’. | | | Kimberley Centre | The last residential institution for people with learning disabilities that closed in 2006. | | | MidCentral area | The MidCentral area has the same geographic boundaries as the MidCentral District Health Board (DHB) which is a North Island DHB area that covers from Otaki / Te Horo in the south, to Apiti north of Sanson in the north and Dannevirke and south-west to the west coast. | | | MOE | Ministry of Education | | | MOH | | Ministry of Health | | MSD | | Ministry of Social Development | | NASC | | Needs Assessment and Service Coordination service. The NASC within the MidCentral DHB area is Enable NZ. | | ORS | | Ongoing Resource Scheme (MOE) | | People First | | Self-advocate organisation for people with learning disabilities | | PPPR Act | | Protection of Personal and Property Rights Act 1988 | | SCBA | | Social Cost Benefit Analysis | | SD | | Standard Deviation | | Survey Items | | Questions or statements in the survey documents requiring a response | | Stakeholders | | Includes Government Ministries, NGO and governmental organisations associated with disability, providers, DPOs and national family organisations | | SWB | | Subjective wellbeing: people making their own assessment of their happiness or wellbeing | | Universal services | | The health, education and other community services available to all New Zealanders | | VHN | | Very high assessed need; based on the needs assessment done through Enable | | WMW | | Wilcoxon Mann-Whitney test for non-parametric statistics | |  |

1. For more information about Mana Whaikaha and the MidCentral area trial, see [www.manawhaikaha.co.nz/about-us/mana-whaikaha/](http://www.manawhaikaha.co.nz/about-us/mana-whaikaha/). [↑](#footnote-ref-1)
2. The IDI stands for the Integrated Data Infrastructure. The IDI is a linked longitudinal dataset that combines unit-record administrative information from a range of agencies and organisations. The IDI is maintained by Statistics New Zealand under strict privacy and confidentiality protocols. [↑](#footnote-ref-2)
3. Social Cost Benefit Analysis. [↑](#footnote-ref-3)
4. See [www.enablinggoodlives.co.nz](http://www.enablinggoodlives.co.nz) [↑](#footnote-ref-4)
5. In particular, people can collude quite unconsciously in their own predicament (hegemony). [↑](#footnote-ref-5)
6. See in particular the theory of homeostasis. This suggests that people appear well adjusted on subjective indicators but can live in circumstances that do not help them maintain or improve aspects of their personal or physical lives. Cummins, R.A. (2005). Moving from the quality of life concept to theory. *Journal of Intellectual Disability Research, 49*(10), pp. 699-706; Cummins, R.A. (1995). On the trail of the Gold-Standard for Subjective Well-Being. *Social Indicators Researchers, 35*, 179-200. [↑](#footnote-ref-6)
7. https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services. [↑](#footnote-ref-7)
8. There were insufficient numbers of people only with sensory impairments (and no other disabilities) to include in this survey. People with Sensory Impairments are likely to access support services through agencies other than the NASC, such as Blind Foundation and Deaf Aotearoa. [↑](#footnote-ref-8)
9. For a small number of people (n=27) in the July 2018 DSS data the level of assessed need is rated as ‘low’. [↑](#footnote-ref-9)
10. A further 0.6 percent identified as gender diverse. [↑](#footnote-ref-10)
11. Eleven people in total including other Europeans (6 people), two people who identified as Asian, two Fijian Indian and one person who identified as Pasifika. [↑](#footnote-ref-11)
12. DSS MidCentral population figures derived from the Enable client database for MidCentral 2018. [↑](#footnote-ref-12)
13. Typically supporting up to six people. [↑](#footnote-ref-13)
14. The remainder include two people with physical disabilities who reside in rest homes, and three who live in residential homes. [↑](#footnote-ref-14)
15. Including themselves. [↑](#footnote-ref-15)
16. Kimberley Centre was the last total institution for people with learning disabilities. It was located in Levin (MidCentral area) and many of those who left were relocated in the same region. [↑](#footnote-ref-16)
17. DSS records only refer to ex-Kimberley residents with reference to day service packages. These records were confirmed (with one addition) from conversations with respondents during interviews. [↑](#footnote-ref-17)
18. Regardless of level of assessed need. There were 38 adults with learning disabilities living in community residential homes, 27 used proxy respondents or a mix of a proxy respondent for some information and information gathering from the service by the interviewer for non-subjective information (two cases). [↑](#footnote-ref-18)
19. N=35 people in total receiving only HM&PC support including n=31 adults with physical disabilities, n=2 children and young people (one each with learning disability and ASD) and two more adults (one each with learning disability and ASD). [↑](#footnote-ref-19)
20. Also see the Glossary of abbreviations and terms, page 94. [↑](#footnote-ref-20)
21. <http://www.enablinggoodlives.co.nz/> and <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf> [↑](#footnote-ref-21)
22. There were insufficient numbers of people in the Pasifika and Asian (n=3 in total) categories to provide a viable comparison. [↑](#footnote-ref-22)
23. Defined as 17 to 65 years of age and not in school [↑](#footnote-ref-23)
24. Gallup World Poll. Bjørnskov, C. 2010. How Comparable are the Gallup World Poll Life Satisfaction Data? *Journal of Happiness Studies*, *11* (1), 41-60. [↑](#footnote-ref-24)
25. In the case of disabled persons survey, a staircase. [↑](#footnote-ref-25)
26. WMW=3.2, p<0.001, df=66. Diff in mean=2.0, *t=*3.5, *p<*0.001. There were only three adults with ASD who provided self-reports for SWB material. Adding them in with self-reporting adults with learning disabilities decreases the mean to 7.1 (2.3). WMW=2.8, p<0.01, df=69. Diff in mean=1.7, *t=*2.9, *p<*0.01. [↑](#footnote-ref-26)
27. Fifteen people with physical disabilities were scoring lower on the ladder compared with 28 people scoring 5 or more. [↑](#footnote-ref-27)
28. From self-descriptions and information obtained from the DSS database, July 2018. [↑](#footnote-ref-28)
29. Self-reports only for people with physical disabilities. [↑](#footnote-ref-29)
30. From 28 different people (some people belonged to multiple clubs, groups or organisations). [↑](#footnote-ref-30)
31. From 15 different people. [↑](#footnote-ref-31)
32. 79 and 27 percent respectively. [↑](#footnote-ref-32)
33. van Campen, C. and van Santwoort, M. (2013). Explaining low subjective wellbeing in persons with disabilities in Europe: The impact of disability, personal resources, participation and socio-economic status. *Social Indicators Research*,111, 839-854. [↑](#footnote-ref-33)
34. NB, learning disability *and* ASD in this case (as some previous comparisons only used ID adults). Three adults with ASD provided self-reports. [↑](#footnote-ref-34)
35. Thirty-three percent lived with family. [↑](#footnote-ref-35)
36. E.g. Kersh, J., Corona, L, and Siperstein, G (2013). Social well-being and friendships of people with intellectual disabilities, In Wehmeyer, M.L. (ed.). *The Oxford Handbook of Positive Psychology and Disability*. Oxford University Press; Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities*, 17, 191–197; Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 145–157. [↑](#footnote-ref-36)
37. WMW=3.8, p<0.001, df=80 learning disability versus physical disability. Diff in mean=1.5. [↑](#footnote-ref-37)
38. Similarly, only 58 percent of adults with learning disability or ASD and who have VHNs believed they were understood when they communicate (all of most of the time). This contrasts with 75 percent of adults with learning disability and ASD with high and moderate assessed needs. [↑](#footnote-ref-38)
39. From n=33 of people who did respond to this question. [↑](#footnote-ref-39)
40. The total number of people in the residential homes sample for adults with learning disabilities was n=37. However, non-responses for these questions was high (51, 65 and 60 percent respectively) creating a sample size of n=18, 13 and 15 respectively). The lack of responses indicates respondents (mostly proxies) simply chose not to answer, did not feel they could answer for the person or did not believe the question was relevant. [↑](#footnote-ref-40)
41. Families or young people may also receive such things as only DHB support (21 percent), behaviour support (two people or five percent) or HM&PC support (18 percent). [↑](#footnote-ref-41)
42. (2017) <https://www.statista.com/statistics/669122/americans-current-relationship-status-by-age/>. [↑](#footnote-ref-42)
43. Equivalent statistics for New Zealand are not available since only married/civil union rates seemed to be available. Not being married or in a civil union does not necessarily mean single. In New Zealand statistics 74% of men and 64% of women aged 25-29 years of age had never been married, also 16% and 13% of 45-49 year olds and 5% and 4% of 65+ year olds had never been married (2006 census) archive.stats.govt.nz/~/media/Statistics/browse.../3-mcud.xls also see 1999 statistics http://archive.stats.govt.nz/browse\_for\_stats/people\_and\_communities/marriages-civil-unions-and-divorces/marriage-and-divorce-in-nz.aspx [↑](#footnote-ref-43)
44. Across all age groups. [↑](#footnote-ref-44)
45. Nine percent of learning-disabled adults reported being in a short- or long-term relationship with another person who does not live with them. These relationships may or may not be intimate. [↑](#footnote-ref-45)
46. For just adults, 63 percent indicated they had friends outside of where they lived. [↑](#footnote-ref-46)
47. WMW=2.5, *p<*0.01, df=41. Diff in mean=0.8. [↑](#footnote-ref-47)
48. Not statistically significant. [↑](#footnote-ref-48)
49. Including grocery stores, shops in general, mall or plaza. [↑](#footnote-ref-49)
50. Including any area where people can go for walks or picnic such as gardens, city and forest parks, and beaches (sports ground were considered separately). [↑](#footnote-ref-50)
51. Including Netball, Softball, Cricket, Rugby, Judo, Indoor Bowls. [↑](#footnote-ref-51)
52. Two people were in a brass band. [↑](#footnote-ref-52)
53. Often includes swimming, Ten Pin bowling, Bocce, weight lifting, track. [↑](#footnote-ref-53)
54. Gym and Bocce Club. [↑](#footnote-ref-54)
55. These included membership of *People First, Multiple Sclerosis Society, Stroke Foundation, Hearing Association, Cerebral Palsy Association, Parent to Parent, CCS Disability Action, Network group (Community Connections), Circle of Friends (Options)* and the *Stewart Centre.* [↑](#footnote-ref-55)
56. Including three belonging to a marae, five belonging to the Kumbaya (ex-Kimberley) fellowship group, two with youth groups (Teenzone, church youth group), two with Cosmopolitan Club and two in Kapa Haka groups. [↑](#footnote-ref-56)
57. A Christian fellowship group set up for people who left Kimberley Centre where they can reconnect. [↑](#footnote-ref-57)
58. Forty-three percent compared with 30 percent for children and young people, WMW=2.1, *p<*0.02, df=76. Diff in mean=0.5, *t*=2.6, *p<*0.01. [↑](#footnote-ref-58)
59. Thirty-two percent compared with three percent for children and young people, WMW=2.2, *p<*0.02, df=76. Diff in mean=0.7, *t*=2.9, *p<*0.01. [↑](#footnote-ref-59)
60. WMW=2.6, *p<*0.01, df=32, (diff in mean=1.1) regarding the difference between residential and supported living. Comparisons with HM&PC only are not significant. [↑](#footnote-ref-60)
61. WMW=2.8, *p<*0.01, df=35, diff in mean=1.1, *t=*2.8, *p<*0.01. [↑](#footnote-ref-61)
62. Defined as ‘get out more’, ‘get out of the house’, join a club or group in order to broaden community experiences. [↑](#footnote-ref-62)
63. Defined as improve health, get well, lose weight, progress (physically). [↑](#footnote-ref-63)
64. Defined not having a condition, to be cured, not to be sick/ill, to get better (with reference to a progressive condition). [↑](#footnote-ref-64)
65. For example, living in a different home (4 people), cooking/baking (3 people), getting a driver’s licence or being able to drive (3 people), being able to work in the garden (2 people), being able to contribute through voluntary work (3 people), going to shows or concerts (2 people), learning to swim, doing more walking, becoming a singer, writing a book, getting a mobility scooter, doing crafts, going on train rides, joining a Menz shed, joining the Cosmopolitan Club, flying a plane, making YouTube videos, writing a computer programme, bee keeping, various types of sport (4 people) and getting some needed equipment in place (2 people). [↑](#footnote-ref-65)
66. WMW=3.5, *p<*0.001, df=31, diff in mean=1.0. [↑](#footnote-ref-66)
67. Although this result is not statistically significant due to the number of people in both groups who did believe they were encouraged to think about what they wanted in their own life, all or most of the time (61 and 70 percent respectively). [↑](#footnote-ref-67)
68. WMW=2.6, *p<*0.01, df=91, diff in mean=0.6, *t=*2.7, *p<*0.01. [↑](#footnote-ref-68)
69. Not statistically significant, diff in mean=0.6, *t=*1.94, *p<*0.029 (not significant). [↑](#footnote-ref-69)
70. WMW=2.7, *p<*0.01, df=19, diff in mean=1.1, *t=*2.9, *p<*0.01. [↑](#footnote-ref-70)
71. WMW=3.4, *p<*0.001, df=26 (diff in mean=1.3) residential versus supported living. Also, residential versus HM&PC only indicated a significant difference between them of WMW=2.3, *p<*0.01, df=32 (diff in mean=0.9). [↑](#footnote-ref-71)
72. WMW=2.6, *p<*0.01, df=50, diff in mean=0.8, *t=*2.8, *p<*0.01. [↑](#footnote-ref-72)
73. Compared with supported living WMW=1.9, *p<*0.027, df=53, ie, not significant. Diff in mean=0.6. [↑](#footnote-ref-73)
74. Only five individuals (7 percent) had at least one NCEA level 1, or school certificate level qualification or higher. [↑](#footnote-ref-74)
75. These included land-based training, an online language course, computers at polytechnic, a health course (6 weeks), personal trainer qualification, “modified” course at polytechnic in woodwork, design course, UCol World of Work I & II (plus a first aid certificate), Māori at Wānanga in Palmerston North, Maths (by correspondence) NCEA level 2. Two more people indicated courses related to computing (at a day service) and kapa haka. [↑](#footnote-ref-75)
76. Or 29 percent of all adults (31 percent of all adults did not provide a response to this survey item). [↑](#footnote-ref-76)
77. Only one person with physical disabilities cited a need for support workers. Twenty-eight percent of people with learning disabilities or ASD cited cost as a barrier. [↑](#footnote-ref-77)
78. People at school included individuals up to the age of 21. This included 86 percent of all children and young people (under the age of 18) or 81 percent of all people up to and including 21 years of age. [↑](#footnote-ref-78)
79. Resource Teacher: Learning and Behaviour (RTLB) [↑](#footnote-ref-79)
80. The Ongoing Resourcing Scheme (ORS). ORS is provided to a student with severe to extreme difficulty in any of five areas of need (learning, vision, hearing, physical needs, or language/social communication) or where a student has moderate to high difficulty with learning and very high needs in any two of the five areas of need. According to the Ministry of Education websites, “ORS is managed by the Ministry of Education, Special Education at local district level and by a number of delegated schools known as Specialist Service Providers (SSPs)”. <http://education.govt.nz/school/student-support/special-education/ors/overview-of-ors#HowIsORSManaged> [↑](#footnote-ref-80)
81. The Youth 2000 survey conducted by the University of Auckland in 2012 indicated bullying was reported in 6 percent of students at school, with rates not changing dramatically since the survey began in 2000. Rather rates of cyberbullying were on the increase over the time period. Clark, T. C., Fleming, T., Bullen, P., Denny, S., Crengle, S., Dyson, B., Fortune, S., Lucassen, M., Peiris-John, R., Robinson, E., Rossen, F., Sheridan, J., Teevale, T., Utter, J. (2013). Youth’12 Overview: The health and wellbeing of New Zealand secondary school students in 2012. Auckland, New Zealand: The University of Auckland https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/ahrg/docs/2012-overview.pdf [↑](#footnote-ref-81)
82. Where employment was defined as receiving payment. For people with physical disabilities employment included a high frequency of full-time and professional employment (for example, journalism, teaching, nursing, horticulture, science) whereas, many adults with learning disability and ASD were more often employed part-time and sometimes with reduced hourly rates (for example, paper runs, business enterprises). [↑](#footnote-ref-82)
83. Working age (17 to 65) and not in school. [↑](#footnote-ref-83)
84. Only 45 people responded to this survey item (or 66 percent of all adults). [↑](#footnote-ref-84)
85. In 2018, the median annual household income from Government benefits, excluding superannuation and war pensions, was $11,262 with a mean of $14,651. The median for people on superannuation and war pensions was $17,801 with a mean of $18,839: <https://figure.nz/chart/OToNBIID6B7ZkZlp-Scm6oim0HTjX7LB2>. [↑](#footnote-ref-85)
86. Eleven disabled people and five whānau in total freely raised issues about transport without prompting (word searches, car, cars, transport, taxi, scooter). [↑](#footnote-ref-86)
87. All children and young people and five (of nine) adults with ASD live with family/whānau. [↑](#footnote-ref-87)
88. For example, eight people with physical disabilities stated they could not afford dentists, seven people stated cost of transport was an issue, six people believed they could not access the community in various ways due to cost, and nine people thought they could not pursue further education due to cost. [↑](#footnote-ref-88)
89. For a 95% confidence interval. [↑](#footnote-ref-89)
90. Adults only are used for people with learning disabilities as all those with physical disabilities were adults. [↑](#footnote-ref-90)
91. There were insufficient numbers of adults with a primary diagnosis of ASD (n=7) to separately include in this figure. [↑](#footnote-ref-91)
92. WMW=2.2, *p<*0.01, df=83. Diff in mean=0.6, *t=2.3,* p<0.01. [↑](#footnote-ref-92)
93. The majority of whom are proxies (typically close whānau such as a parent). [↑](#footnote-ref-93)
94. WMW=2.6, *p<*0.01, df=91 learning disability versus physical disability. Diff in mean=0.6, *t=*2.7, *p<*0.01. For further discussion of the results for this item see section 5, Personal Development and Planning. [↑](#footnote-ref-94)
95. WMW=2.5, *p<*0.01, df=91. Diff in mean=0.8. [↑](#footnote-ref-95)
96. That is, support workers were described as being ‘good, nice, consistent, dedicated’ etc. [↑](#footnote-ref-96)
97. As a general statement (kept busy, occupied, getting out and about) or with regard to specific things such as being involved in sport, gym, swimming, going to cafes, shopping and bars etc. [↑](#footnote-ref-97)
98. This covered three questions, two directly related to supports (‘what do don’t you like about the supports you receive?’, and ‘if you could change one thing about your support, what would it be?’) while the third related to the person themselves, ie, their own goals or aspirations (‘if anything were possible, what are some things you would like to achieve, start doing, or do more of?’). [↑](#footnote-ref-98)
99. N=30 and n=34 responses were made for each of these questions respectively. [↑](#footnote-ref-99)
100. This figure includes only people with VHNs with learning disabilities living in community residential homes. Regardless of assessed need the figure is 71 percent. [↑](#footnote-ref-100)
101. For example, for the Likert Scale item ‘my support occurs when I need it in my life’ (4.4), 80 percent indicated this was the case all or most of the time. Further, 78 percent believed supported living helped them pursue their own interests all or most of the time (for all people receiving supported living). [↑](#footnote-ref-101)
102. Seventy-eight percent indicated that their supports helped them connect to people and places that are important to them and 73 percent believed they were supported to be an active member of their community all or most of the time. [↑](#footnote-ref-102)
103. Those providing self-reports only (n=21). [↑](#footnote-ref-103)
104. ‘Supports help me pursue my own interests’ WMW=3.0, *p<*0.001, df=43. Diff in mean=1.1, *t=*3.4, *p<*0.001. [↑](#footnote-ref-104)
105. ‘My supports help me connect to people and places that are important to me’, WMW=2.4, *p<*0.01, df=43. Diff in mean=1.3, *t=*2.9, *p<*0.01. [↑](#footnote-ref-105)
106. This group was chosen because they are not a residential sample and are not primarily supported through the carer support subsidy (also 88 percent of the people on supported living are people with learning disabilities). [↑](#footnote-ref-106)
107. And 35 percent of all physically disabled people. [↑](#footnote-ref-107)
108. People with physical disabilities with only HM&PC support. [↑](#footnote-ref-108)